



A Question of Location - Life with Fatigue after Stroke

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Publication date:
2014

Document version
Early version, also known as pre-print

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Citation for published version (APA):
Andersen, M. (2014). *A Question of Location - Life with Fatigue after Stroke*. Det Humanistiske Fakultet, Københavns Universitet.

A Question of Location – Life with Fatigue after Stroke

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02.09.2013

PREFACE	1
INTRODUCTION – A QUESTION OF LOCATION.....	3
THE STROKE	4
FATIGUE AS AN EXPERIENCE AND AS A PHENOMENON.....	7
LOCATING FATIGUE.....	9
THE OUTLINE.....	15
INTRODUCING FATIGUE THROUGH ACEDIA AND NEURASTHENIA.....	19
THE EXPERIENCE OF A CONDITION.....	21
FATIGUE AND ACEDIA.....	25
NEURASTHENIA AND FATIGUE	36
A DIGRESSION AND A PERSPECTIVE.....	46
LOCATED CONCLUSIONS.....	50
AN ETHNOLOGICAL FIELDWORK.....	52
PROJECT AND FIELDWORK	52
LOCATING THE LACK	53
CONTACT	56
AN ETHNOLOGICAL INTERVIEW	57
THE (MEDICAL) PROFESSIONAL – ETHICS	60
A DISRUPTED RETURN TO EVERYDAY LIFE	64
THE CONCEPT OF EVERYDAY LIFE	64
AN EXISTENTIALIST PHENOMENOLOGICAL APPROACH TO EVERYDAY LIFE	67
A DISRUPTED RETURN TO EVERYDAY LIFE.....	71
FATIGUE AS A STIMMUNG	81
THE NARRATIVES OF FATIGUE	88
THE NARRATIVE AS COMMUNAL	100
THE LETTER THAT ALWAYS ARRIVES AT ITS DESTINATION!	105
THE REGIMES OF HOPE.....	110
THE TYRANNY OF POSITIVE THINKING	111
WILLFUL PERSPECTIVES	116
LOCATING PAIN	119
A BODY IN PAIN.....	119
THE PRESENCE OF PAIN.....	122
PAIN AND SLEEP – PAIN AS SLEEP	124

PAINFUL TRANSITIONS	126
MANAGING PAIN	127
THE ULTIMATE LOCATION	129
BEING NORMAL – STIGMA AND PROGRESS	131
THE STIGMA	137
THIS “OTHER” BRAIN OF MINE	140
THE OTHER.....	140
THE SELF AND THE OTHER	143
THE OTHER BRAIN OF MS. PETERSEN	147
THE OTHER OF MR. JENSEN	149
THE INTEGRATION OF THE BRAIN.....	152
THE DISCIPLINED OTHER	154
THE OTHER IS A BRAIN	158
A QUESTION OF LOCATION	160
LOCATING PLACE AND PRACTICE	161
THE STROKE REVISITED	166
PERSPECTIVES	167
A FINAL LOCATION	169
BIBLIOGRAPHY	171
FIELDWORK INDEX	180
MAIN INFORMANTS.....	180
OBSERVATIONS	182
RESUMÉ	183
SUMMARY	184

FATIGUE

Evening's fall –
and still they call.
The birds I shaped, their faint,
tolling complaint

Gray Walls come
down on all lands.
My hands become,
once more, my hands.

I cannot bound
what I did love;
What's all around,
I cannot leave.

It all recedes.
Ascending dark.
For me, no defeats –
must be life's arc

- Hannah Arendt 1923-26 (Arendt and Heidegger 2004)

Preface

To be fatigued seems like such a trivial everyday experience. Most of the time we know that we will get fatigued at some point during the day, and we will incorporate this fatigue into our everyday lives. We try to discipline our lives so that the fatigue arrives at the right time during the day, and if it arrives early, say, during a tedious meeting at one's workplace, we may try to counter it through the use of stimulants such as coffee, or we may resolve to more experimental methods such as power napping. Fatigue has a place in our lives as the silent bystander that sometimes gets in the way of our dealings in everyday life. To be fatigued after stroke on the other hand is something else. A relationship to the silent bystander has been altered, and it is the management of this relationship that I will be looking into in the present thesis. How does a person that has had a stroke and reports post-stroke fatigue manage the experience of fatigue in everyday life? What is the relationship between the fatigue and the stroke, and how is the experience of fatigue perceived?

During the years of writing this thesis, fatigue has come to the absolute forefront of my attention, and has shown itself in all the ways in which it is constantly put forward in the media, almost always in combination with greater efficiency/productivity or better health, or both at the same time. That fatigue is truly on the political agenda, and has been so for quite a number of years, does not make experiencing an "un-normal" fatigue any easier for the person in question, and the web of moral and pathological associations of fatigue has been spun deep into the fabric of society. Personally, I have experienced a huge degree of sympathy for the people who regularly deal with this "un-normal" fatigue, be it due to a stroke, or to any other event or situation. Not only are they struggling with their own expectations, but they also fail to meet the expectations of others. Thus it has come to my acute awareness: that fatigue is tied to social structures and personal experiences; that it is a feature of almost everyone's lives that is constantly regulated, monitored and registered; that it has a long cultural history and has played an intrinsic part in nation-building, and that it is part of the way in which we identify ourselves as human beings in the world; i.e. that how we handle fatigue has become a defining feature of our being.

First of all I want to thank all the informants who agreed to take part in this study and for sharing so much of their lives with me. For putting up with me in the process of writing this thesis, I owe a big thanks to my wife Line Richter sine qua non and to Mark Vacher who convinced me that fatigue was not something to get bored with. Furthermore, I owe a great thanks; to both of my primary supervisors during the period of writing the thesis Lene Otto and Tine Damsholt; to my secondary supervisor Hysse Birgitte Forchammer; to all the wonderful and supportive colleagues at the Department of Ethnology and to family and friends who have helped me to get through finishing the thesis. A special thanks to Sharon Kaufman, Vincanne Adams and Dorothy Porter at UCSF School of Medicine; Anthropology, History and Social Medicine for making my six months in San Francisco an extraordinarily educational and enjoyable experience.

Finally, a great thanks to Amy Clotworthy and Monica Hylander Friis for the language revisions, to Toke Kyed Amlund for help with the layout, and to nurse Mette Kjærsgård and Hjernesagen for being so kind and supportive in helping me find the informants for this study.

Introduction – A Question of Location

In the summer of 2010, the PhD proposal for the present thesis was accepted. The thesis attempts to answer the overall PhD advertisement: *A fieldwork oriented cultural analysis of how fatigue is diagnosed, treated, understood and managed with an emphasis on the relation between science and everyday life*¹. In collaboration with Glostrup Hospital, the proposal presented a specific ethnological take that emphasized everyday life to address an overall question of the experiences of fatigue among people who have had a stroke.

If one were to draw up the roads travelled when writing a thesis on a map, one would most likely end up with a somewhat defaced map with lines drawn everywhere. Sometimes the lines would stop at a dead end only to return to the initial starting point; sometimes the lines would become thicker and thicker as the same route had been travelled numerous times; and sometimes you would find that a road may bring you to places that end up restructuring your thesis completely, creating a new starting point. In my case, it was one sentence that eventually presented the road that came to orient this thesis. As a strong proponent for the integration of the žižekian version of lacanian psychoanalysis in the ethnological curriculum, I had done my Master's thesis heavily relying on psychoanalysis. In my PhD thesis, I wanted to continue what I, at the time, saw as a kind of pioneer-work in ethnology. Fully aware that psychoanalysis was, and still is, somewhat contentious in social science, I wished to incorporate psychoanalysis in such a way so as to enlighten the ethnological reader on the way in which psychoanalysis could add to cultural analysis. That psychoanalysis is still very contentious became apparent to me when I explained my intention to make room for psychoanalysis in the thesis to a good colleague of mine. This colleague had always been distrustful of psychoanalysis (being a strong proponent of Foucault) and I was thus met with a question I had heard many times before, but which in this context made “serendipitous sense”: “Where is the psyche located?” The obvious psychoanalytical answer is that the psyche is a force composed of the id, the superego and the ego, and the question of its location seems to indicate a wish to institute the psyche with a sense of biological reality in terms of being able to find it inside the body. In that

¹ Translated from: “En feltarbejdsbaseret kulturanalyse af hvordan træthed diagnosticeres, behandles, forstås og håndteres med særlig vægt på relationen mellem videnskab og hverdagsliv.”

sense, the question was reminiscent of the century long debate on the location of the soul, but the subtext of the question was subtler than that. As with the soul, the question was directed at the idea of the psyche as an ontological entity. In essence, it implied that it does not exist because we can't locate it. This reminded me of something else, which had been one of the reasons behind writing the PhD proposal: that *fatigue* was not possible to *locate*. When the project was formed, the issue of post-stroke fatigue had been an often-reported sensation among patients, yet a lack of correspondence between the reported sensation of fatigue and the size, or the location, of the potential infarct presented somewhat of a riddle. In effect, the medical sciences had to rely on a reported subjective experience that was not localizable and which could not promote an overall universal remedy for its potential cure. Essentially, what the question concerning the location of the psyche made me aware of was a similar yet qualitatively different conundrum "Where is fatigue located?"²

The Stroke

To put it mildly, there is no lack of literature on stroke. Ranging from self-help books on how to prevent strokes (Spence 2006), cope with strokes (Raymond 2009), etc. to neuroscientific articles on the correlation between strokes and genetics (Hassan and Markus 2000). Strokes are a major issue in almost all areas of society. Class (McFadden et al. 2009), gender (Petrea et al. 2009), race (Gaines and Burke 1995) and sexuality (Valanis et al. 2000) are just some of the parameters that are taken into consideration when the susceptibility of stroke is assessed and when looking at the impact of stroke. Not only from an individual perspective, but also from a societal standpoint, it makes sense why strokes are as widely researched as they are. As a statistic from the "American Heart Association" shows, although the rates in CVD (cardiovascular disease) have dropped in recent years, leading to fewer fatalities (Go et al. 2013), strokes are still a major cause of deaths and long-term disability. In an article from 2003, Jan A. Staessen et al. state that worldwide, stroke is second to ischemic heart disease as a cause of death (Staessen, Kuznetsova, and Stolarz 2003). A great deal of emphasis has been put on prevention, and lifestyle changes

² Although psychoanalysis did not play as significant a part as I had initially planned for, in part due to the fact that I allowed my choice of theory to be dictated by my empirical material, it still has a re-occurring presence throughout the thesis, which, however, is due to the fact that it proved valuable in the analysis of parts of my empirical material.

in particular have been promoted as what might lower the risk of stroke (Kurth et al. 2006). Identifying a number of risks as disparate as tobacco use to level of education (Galimanis et al. 2009), strokes have manifested themselves outside the confines of the body.

Both qualitative as well as quantitative studies on stroke are numerous. A large amount of the quantitative publications are attributed to neurological journals with a focus on the measurable impact of stroke, whereas many of the qualitative publications are within nursing journals that focus on care after stroke. As the scope of the thesis is limited to qualitative material, I limit the following brief exposition of literature on stroke to the literature that primarily deals with strokes from a qualitative perspective. Furthermore, all the literature that I have included in this exposition relates to post-stroke. Far from being an exhaustive presentation of qualitative studies on stroke, this brief exposition is added in order to portray the breadth of qualitative studies on stroke – simultaneously allowing me to position myself in relation to these studies.

Although it may be a somewhat rough outline, according to the review article “Qualitative Studies of Stroke” from 2002 (McKevitt et al. 2004), qualitative post-stroke publications can be grouped into those that focus on: *acute care, rehabilitation therapies, life after the acute event, carers’ experiences and needs, and community services* all with multiple overlaps (ibid.). As I am particularly concerned with *life after the acute event*, I should like to tighten the exposition further by focusing primarily on the literature within this category in general. Within this category, there is a predominance of literature describing stroke as the experience of a *loss*; loss of functional ability and independence (O’Connell et al. 2001; Hilton 2002), sociality (Mumma 2000; Pound, Gompertz, and Ebrahim 1998b; Burton 2000), identity (Ellis-Hill, Payne, and Ward 2000; Doolittle 1992; Charmaz 1983) etc. Being such a loss, stroke has, since sociologist Michael Bury and anthropologists Gaylene Becker and Sharon Kaufman began using the word, been described as a disruption with an emphasis on the disruptive (Becker 1993; Bury 1982)³. This means that life after stroke is characterized as an uncertain and variable time, in which frustration is a constant companion (Becker and Kaufman 1995). As Becker notes in her work *Disrupted Lives* (Becker 1997), which deals with stroke patient’s experiences, they all attempt to create meaning in this new and

³ In the chapter “A Disrupted Return to Everyday Life”, I will discuss the concept of the stroke as disruptive in more detail.

uncertain time. However, as Becker also notes, this meaning is not found in a “normative definition of disablement” (Clarke 2009), but rather in relation to their own perceptions of what is important in their lives. Numerous studies have since addressed this point (Clarke and Black 2005; Lister 1999; Pound, Gompertz, and Ebrahim 1998b; Doolittle 1990); in one study, it is argued that stroke survivors assess their “disabilities against a variety of benchmarks” that relate to the survivors lived experiences as opposed to those of a formal assessment (Gubrium et al. 2003), while another study argues that the stroke survivors operate with individual and personal yardsticks that relate to their lives before stroke to assess their current state (Dowswell et al. 2000), something that is also taken up by Kaufman (Kaufman 1988b). As a part of identity work post-stroke, it is often argued that certain acts performed pre-stroke become more important and accentuated. Although the actual physical performance of these acts post-stroke may be impossible, other links are established, which ensure the “maintenance” of an identity (Becker 1993).

Most of the publications referred to are authored by social scientists, and are in somewhat of a contrast to the scores of self-help publications and biographies promising further insight after stroke (Taylor 2006), as well as emphasizing how individual resilience, support from family and hope may give stroke victims their lives back (McEwen 2009; Klein and Blackbridge 2000; Maxwell, Maxwell, and Lamont 2008; McCrum 1998). As the short exposition indicates, most of the articles that look at the experience of life after stroke – apart from describing the experience as a loss – describe it as an attempt to return what has been lost; maybe not in exactly the same way as pre-stroke, but in a way that meaningfully connects to a former identity.

Through an empirical fieldwork, the present thesis will add to the literature on *life after the acute event* by examining how a stroke is a disruption that *dislocates* the experience of fatigue. The fieldwork for the thesis has been conducted among people who have had a stroke and who report post-stroke fatigue. By conducting interviews in the homes of the informants as well as doing observations at Glostrup Hospital, the empirical material on which this thesis rests, has been generated. This empirical material has prompted me to look at the location of fatigue in everyday life, and in the thesis I will approach how location may provide meaning to the informants’ experiences of fatigue. Thus, I will

examine how a range of new locations may become important to the informants, and how these new locations may figure in the construction of a meaningful life after stroke.

As the exposition demonstrates, stroke is a disruption and, as such, an event that instigates a change to the experience of fatigue. Thus, it institutes a range of new locations as well as provides old locations with a new force. For instance, concentrating may suddenly become a more forceful location of fatigue that institutes a management of the location; e.g. not concentrating too much etc. Simultaneously, the stroke may change one's look on being and, in that sense, I will argue that the fatigue following a stroke may become a reminder of the event of the stroke – an event that, in most cases, is associated with one's own mortality. When fatigue is presented thus, I will argue that it becomes increasingly important to locate fatigue, as doing so may remove the sensation of one's mortality and make the experience manageable. The fatigue has changed due to the stroke, and its possessive nature has become more immanent – and thus more difficult to fight against – but in the same process, it makes one aware of one's existence.

In other examples, I will examine how fatigue after stroke may manifest itself as what German philosopher Martin Heidegger (1889-1976) called a *stimmung*. Stimmung, which roughly translates as “mood”, is the lens through which the world is experienced. In that sense, one is always in a certain *stimmung*, but since the *stimmung* is what one is in, the necessary distance between the *stimmung* and I conceals the *stimmung*. In the case of fatigue as a *stimmung*, I will look at what part location plays for the person experiencing the fatigue and for their possible spouses, and how this affects their everyday life.

Fatigue as an Experience and as a Phenomenon

Before moving on to describe my approach that emphasizes location, I wish to draw attention to the fact that the thesis places itself in a limbo between a traditional phenomenological approach and a more constructivist approach. At the very beginning of writing the thesis, the question as to what fatigue *is* was a considerable question. In essence, it was a question that pointed to the fact that I would be researching something I could not define and had a hard time explaining. Looking to language and discourse provided little consolation, and people couldn't help but try to point me in all the different directions in which the word is used. Even my translation of the Danish word “træthed” to

“fatigue”, posed issues in terms of whether fatigue and tiredness were used to describe two different experiences. Furthermore, it pointed to the question of whether fatigue could be divided into categories of normal and pathological; if there were two qualitatively different types of fatigue, then should I be focusing on one specific kind? In effect, researching fatigue among people who have had a stroke proved immensely difficult both in terms of language as well as in terms of experience.

As anthropologists Victor Turner and Edward Bruner point to in *The Anthropology of Experience*, the question is how to overcome the limitations of individual experience when doing ethnographic research (Turner and Bruner 1986, 5). Bruner and Turner attempt to provide an answer by pointing to the hermeneutics of German philosopher and sociologist Wilhelm Dilthey (1833-1911). By doing so, they argue that one may “transcend the narrow sphere of experience by interpreting expressions” (ibid.). For Turner and Bruner this results in a distinction between “mere experience” and “an experience”. Mere experience denotes the passive endurance and simultaneous acceptance of events; it is an individual experience in a temporal flow (ibid. 6 & 35). *An* experience, on the other hand, is an intersubjective articulation of experience, which thus becomes an expression; an expression that breaks with the temporal flow through its construction of a beginning and an end. Some of these expressions may take the form of events that break with the routinized way of living, by way of a shock. From this perspective – as argued throughout the thesis – fatigue is *an* experience that suddenly appears by way of the stroke as well as being *experience*.

However, this distinction did not fully answer the question of the nature of what I would be looking for, except that I would be looking for an experience of something specific that was both individual and intersubjective. Simultaneously, it pointed to the question of whether or not the individual experience could be intersubjective; i.e. if the experience of fatigue as an intersubjective expression corresponded with the individual experience, and how this could be feasible when an experience, as an intersubjective expression, breaks the temporal flow and an individual experience does not – as Turner and Bruner argue:

Although life is a flow, we can never experience that flow directly because every observed moment is a remembered moment. Temporal succession cannot be experienced as such because the very

observation of time fixes our attention and interrupts the flow of experience...(Turner and Bruner 1986, 8)

Dilthey's notion of experience, which Bruner and Turner adopt, corresponds quite well with the post-Romantic tradition of a difference between *Erlebnis* and *Erfahrung*, and thus essentially dilemmas relating to what contemporary philosophers often refer to as *qualia*⁴. In effect, it relates to the idea of a subjective experience that cannot truly be communicated through anything other than by experiencing it oneself – such as mental states of joy, grief etc. This nonetheless seems to institute the idea that there is a certain experience in itself, which is almost comparable to the Kantian *Ding-an-Sich* that conceals its being – although qualia is essentially accessible through experience.

The question of how to examine fatigue as an experience was unanswered and seemed unanswerable right up to the point when I began my fieldwork with the question about the location of the psyche posed by my colleague constantly roaming in my mind. What became apparent in this process was that my informants attempted to make sense of their experience of fatigue by way of locating the experience. However, it also gradually occurred to me that the locations of fatigue were closely tied to a range of other locations post-stroke, and that the location of fatigue had to be understood in relation to these locations. It is these locations and the management of these locations that I explore in the present thesis.

Locating Fatigue

I have made *location* the focal point of my analyses by allowing the concept of location to be the common thread throughout the thesis⁵. In the following few paragraphs, I briefly outline my analytical approach, which besides being a structuring element, represents my aspiration of an original contribution to studies in illness and disease, as well as to Ethnological studies in general.

⁴ Qualia is first used in the work *Mind and the World* by Clarence Irving Lewis (Lewis 1956 [1929]) and it refers to what is directly intuited and cannot be erroneous, as it is subjective; e.g. a colour, etc.

⁵ My use of the concept of *location* should by no means be confused with the use of the concept in the economic “location theory” as developed by Johann Heinrich von Thünen (von Thünen 1966 [1826]), which deals with the geographic location of economic activity.

A central premise of the thesis is that fatigue can be treated as a subjective experience. In order to share the subjective experience and in the same process, *explain* it – *communication* through *location* is essential. In essence, my use of the term *communication* refers to the effort of articulating the subjective experience, while *location* is the explanation/rationale that makes the experience applicable in general – it provides a rationale that seems to go beyond the subjective experience.

In the thesis the concept of location represents an approach to the question of *how* a meaning of experience is created and *why*. To answer the last question, I will argue that locating provides meaning and that meaning makes experiences more manageable. To answer the first question, it is important to stress that location is both place and practice; i.e. an object, an act and an event. Thus, location is an embodied feature of everyday life that is dislocated when stroke happens. The informants in this study attempt to create meaning of their experiences of fatigue by locating their fatigue and through locating, making their fatigue manageable. This process of location happens through multiple areas of everyday life and is structured depending on contexts that ultimately communicate the informants' experiences of fatigue. In that sense location is a way of approaching *how fatigue is in everyday life*.

While arguing for the importance of making experience communicable through location, I also argue that there is a breaking point in which fatigue becomes an all-encompassing experience beyond communicability or location. A point when it changes from being a communicable intersubjective experience to becoming an anti-social un-communicable experience. At this point, one is not communicating anything nor locating, but is consumed by the fatigue. In essence, I operate with – in likelihood, with Turner and Bruner's analysis of *an experience* and *experience* – two kinds of fatigue. The fatigue that is communicable and located, and the fatigue that represents the moment that transcends communication – at this point, it is not so much experienced as it is possessing. I attempt to analyze this kind of possessive experience, not only by making it an experience that one always does when removing experience from temporal flow as Dilthey and Turner suggest, but by approaching it as a *stimmung* (Heidegger 1996 [1927], 128). This approach allows

me to analyze how fatigue may encapsulate one's being and thus be outside the confines of a location.

Throughout the thesis I draw on both an interactionist-constructivist approach as well as on an existentialist-phenomenological approach. The choice of doing so reflects my aspiration to combine the approaches, in order to provide insights into the subject of analysis, although the two approaches are often framed as very disparate. Also, it is my contention that the differences between a phenomenological-existentialist approach and an interactionist-constructivist approach are not unbridgeable. In the much praised *Kvalitative metoder i et interaktionistisk perspektiv* (Järvinen and Mik-Meyer 2005) by anthropologist Nanna Mik-Meyer and sociologist Margretha Järvinen, they argue that the biggest difference between an interactionist-constructivist approach and a phenomenological-existentialist approach lies in the object of study. As they argue, the phenomenological-existentialist concept of the object of study presents the object as a stable phenomenon that may change with time, whereas the object of analysis is multiple, unstable, liquid and partly shaped by the researcher in an interactionist-constructivist approach (Järvinen and Mik-Meyer 2005, 9). While I recognize and acknowledge the difference, I do not fully agree with the extent of the polarization of the two approaches, as presented by Mik-Meyer and Järvinen. It is my opinion that constructivist research is as multifarious as phenomenological research (Schacht 1972), and that this polarization represents a simplification that has prevailed in numerous works of social science. To take a quite illustrative example the phenomenology of Edmund Husserl and the phenomenology of Heidegger do differ to a quite significant degree, and the simplification inherent in the representation of the object as a stable entity within phenomenology is contestable when approaching these differences. As philosopher Richard Schacht presents in the paper "Husserlian and Heideggerian Phenomenology" (Schacht 1972), Husserl's worldview holds that phenomenology represents a reconstruction of knowledge – similar to the reconstruction attempted by Descartes in his meditations – that proposes a transcendental theory of knowledge predicated on the experiences of a transcendental subject/ego (Schacht 1972, 295-296). As Husserl states:

...Phenomenology, it aims at being a descriptive theory of the essence of pure transcendental experiences from the phenomenological standpoint, and like every descriptive discipline, neither

idealizing nor working at the substructure of things, it has its own justification (Husserl 2012 [1913], 143)

Husserlian phenomenology thus holds the transcendental subjective experience to be the gateway to knowledge. However, this transcendental experience is, according to Husserl, in opposition to what Schacht calls “an ordinary experience”. It is a distinct entity that is reached through a phenomenological reduction – a kind of epoché – in which one brackets one’s judgments and regards all experiences as phenomena in a “flow of experiences” (Schacht 1972, 299). This essentially means, as Schacht points out, that:

For Husserl, the task of phenomenology lies elsewhere; it consists in ‘transcendental theory of knowledge’ and ‘the science of transcendental subjectivity’, rather than in the exploration of human experience at the natural standpoint (Schacht 1972, 300)

Heidegger on the other hand, rejects the transcendental subjectivity and, through his concept of Dasein⁶, he situates man as existing in the world – “a world which transcends him and in which he finds himself” (Schacht 1972, 304). This essentially means that man experiences the world, and that this experience cannot be made “presuppositionless”, as Husserl proposes is feasible through phenomenological reduction. Rather a phenomenon, according to Heidegger, is what shows itself in itself, unlike an appearance, which shows itself in something else (Heidegger 1996 [1927], 28). As Heidegger says:

...‘phenomena’ are the totality of what lies in the light of day or can be brought to the light – what the Greeks sometimes identified simply with τὰ ὄντα (entities) (Heidegger 1962 [1927]-a, 51)

Both Heidegger and Husserl emphasize the subjective experience, but other than that they are hugely different in their approach to phenomenology, and in both cases, it is questionable whether the object of analysis, as Mik-Meyer and Järvinen write, is as stable as they present it as being in phenomenology in general. At the same time, one might argue that, as sociologist John Law does in the article “Objects and Spaces” (Law 2002), there is a performative stabilization of relations taking place in a range of studies that tend towards a more interactionist-constructivist position. In essence, any interactionist-constructivist study will necessitate some degree of stabilization of the object of analysis, even when the object is perceived as continually constructed in interaction. To that extent, I see no reason why a certain phenomenological position, such as an existentialist-

⁶ The concept of Dasein is explored in more detail in the chapters to come.

phenomenological as proposed by Heidegger, cannot be combined with a more interactionist-constructivist position, and it is a reluctance to be completely orthodox in either approach that has caused me not to argue more strongly for one approach over the other.

All this being said, the thesis does privilege an existentialist-phenomenological approach over the interactionist-constructivist, and I have simultaneously explored the subject matter through psychoanalytical approaches as well. Rather than attempt to account for how psychoanalysis is compatible with existentialism, as philosopher Simon Critchley does when discussing ethics in *Infinitely demanding: ethics of commitment, politics of resistance* (Critchley 2007), I would emphasize how I have not been rigid in my choice of theory – coupled with my decision to not be too conservative in my theoretical choices – I have had a dialectical approach to my empirical research and my choice of theory; i.e. I have allowed them to inform each other throughout the three years in which this thesis came to life. Thus, it is important to note that the theory applied in the thesis is primarily applied due to its ability to provide further insights into the subject matter. A short note should be added in this respect. During the three years I have been working on the thesis, it has become explicitly obvious that STS (Science and Technology Studies) as well as ANT (Actor Network Theory) have become some of the most dominant theoretical movements related to health and illness in social-scientific research in Europe. Within Ethnology, ANT and STS have figured as a part of the “material turn” (Otto and Kragelund 2005), which continues to be a substantial movement that structures a large amount of the research being done at the department of Ethnology. As ethnologist Lene Otto has pointed out, the material turn is a movement away from culture as representation to a study of how culture is practiced (Jespersen, Melchior, and Sandberg 2006). In that sense, the material turn represents how culture is more than just discourse, as historian Dorthe Gert Simonsen and ethnologist Tine Damsholt point out (Damsholt and Simonsen 2009). In essence, culture is not to be treated as a readable sign, signifying something specific within a semiotic system, but is a wide collection of relational practices. Amongst these practices, objects have emerged as important actors within the field of ethnology and, in many instances, the material turn has quite literally become material, both through the introduction of the separate works of British anthropologists Daniel Miller and Tim Ingold, as well as through the introduction

of the movement of ANT by French sociologist Bruno Latour. As philosopher Graham Harman puts it, Bruno Latour's approach means that:

Every human and nonhuman object now stands by itself as a force to reckon with (Harman 2009, 13)

In that respect, Latour promotes what could be called an “egalitarian” ontology, where humans and objects are actants on the same ontological footing (Harman 2009, 14). In other words, ANT and STS have given credence to objects in an unprecedented extent within social science, and presently this movement is an important actor, not only in studies of health and illness, but also in ethnological studies in general. Nonetheless, what is noticeable in the quote by Harman is the extent to which the description of objects as a force to reckon with almost directly corresponds with the aforementioned approach by Heidegger, which was developed some decades prior to the arrival of ANT and STS. Of course, part of this can be ascribed to Harman's specific reading of ANT and STS as having somewhat similar philosophical agendas as Heidegger's.

In the present thesis, whenever ANT or STS may seem present in the analyses – albeit not explicitly mentioned – it is due to the fact that I am influenced by Harman's reading of Heidegger. A more traditional incorporation of ANT and STS could possibly have provided the present thesis with insights in a range of other areas, and the concept of location could easily have been further supplied by a more meticulous ANT- or STS-based analysis of the impact of different material actors. That I have chosen not to do so does not present an unwillingness towards ANT or STS as theoretically informative to studies of health and illness; rather, it suggests that I have a specific emphasis on fatigue as experienced as a location by a being in the world. In other words, the human subject *is* the central actor in this study, and it is her/his experience of fatigue, and attempt to provide meaning to the fatigue that is emphasized. Whereas objects etc. do appear in the thesis and do have an importance, I do not treat them in isolation as actors that stand by themselves. Instead, I focus on how they show themselves to a being in the world. To be clear, the location of fatigue in objects is not to be understood as objects inflicting their forces (Harman 2009, 15), but as a location of objects that show themselves to a subject/being involved in relations in the world. The objects derive their significance through the subject and the social relations of which the subject is a part. In studying

experiences, a phenomenological and existentialist approach is thus more appropriate than an ANT or STS approach.

Furthermore, it has been my intention to present new approaches to studies of health and illness within Ethnology, as well as within social science in general. I fully acknowledge that phenomenological, narrative and genealogical approaches, all of which are employed in the thesis, have had, and continue to have, an importance in studies of health and illness – my belief, however, is that the present thesis may further contribute to these approaches as well as develop them by means of looking to location. In that respect, location is as much a tool as it is a central approach in the thesis. From an Ethnological perspective, the thesis places itself as an extension of what ethnologist Signe Mellemgaard quotes late professor of Ethnology Bjarne Stoklund as defining Ethnology; namely as the study of how reality is perceived and how people attempt to create order and intelligibility in their world (Mellemgaard 1998). It is my hope that the concept of location – as explored in this thesis – will be accepted as a way to approach this question.

The Outline

The thesis follows a fairly straightforward structure. Beginning with a cultural-historical chapter, I approach fatigue as a phenomenon that has been interpreted in numerous ways throughout history, and which has been located in just as many. Focusing in particular on the way in which fatigue has been posed as a problem, I present the diagnoses of neurasthenia and acedia as genealogically relevant examples of the construction of fatigue as a problem. By showing how the definitions of neurasthenia and acedia as a disease emphasized fatigue as a sign, I depict how the experience became connected to morality and immorality, normality and pathology. Through these examples, I show that locating fatigue was not just a matter of reducing fatigue to certain areas of the body, but was also related to events, acts, status in life etc. Thus neurasthenia and acedia portray how fatigue could be located in multiple places at the same time, and that the communicability of the experience of fatigue was dependent on who experienced the fatigue; that experiencing fatigue was tied to one's place in society, and the location of fatigue equally so. In that sense, the lens of location illustrates how fatigue was not an ontological entity of universal character, and the examples portray how fatigue could be located in demons, in neural

diseases, in class etc.; I argue that fatigue was both a sign and an experience – it was a sign of a certain affliction, and an experience relating to one's place in society.

In the chapter “An Ethnological Fieldwork” I present how the empirical fieldwork was generated and how the question of location came into being the central topic of the thesis. It also expresses my own attempts at locating and defining the object of study, and approaches my initial confusion concerning the relationship between the empirical fieldwork and the theoretical outlook.

In the second part of the thesis, in addition to a short introduction to the concept of everyday life and an outline of the existentialist theory that the thesis embraces in large parts of the analytical chapters, I analyze the relationship between everyday life and fatigue among people who have been struck by stroke. By approaching fatigue as an experience with which one has had a specific relation to throughout life, I attempt to portray the difficulties of dealing with an everyday life that is challenged by the force of a new relation to fatigue. In approaching fatigue as something that is supposed to be structured by everyday life, and as what structures everyday life in the chapter “A Disrupted Return to Everyday Life”, I attempt to illuminate the existential burden of being that may be highlighted by fatigue. In this chapter, I also open the possibility of understanding fatigue as a *stimmung*, and thus the lens through which one experiences and perceives the world. In that sense, it encapsulates one's being in the world.

In the chapters that follow “A Disrupted Return to Everyday Life”, I explore a range of issues in relation to how my informants experience their everyday lives with fatigue. In the chapter “The Narratives of Fatigue”, I analyze the narratives surrounding the changes of everyday life after stroke. Taking up the narrative approach from French hermeneutic philosopher Paul Ricoeur to analyze the construction of narratives as based on the provision of meaning, I look at my informants' narratives and explore how fatigue may be located within these narratives and, to a larger degree, how the stroke is incorporated within these narratives. I expand on this in the chapter “The Narrative as Communal”, where I analyze the communal construction of narratives by those of my informants who I have interviewed alongside their spouses.

In the chapter “Locating Pain” I take a similar approach to pain as the one I have developed in relation to fatigue and try to illustrate how pain is managed by a selection and de-selection of certain acts, objects or events that are associated with pain. By doing so, I portray how pain may be located in these acts, and that pain is managed through this location. This chapter supports my overall argument on the potential applicability of location as a methodological tool, and furthermore points to the way in which different locations interact; i.e. the location of fatigue and the location of pain.

In a continuation of “Locating Pain”, the chapter “Being Normal” treats the way in which notions of normality are intrinsic to the experience of progression after stroke for my informants, and how stigma plays an important part to the experience of progression. Through locating normality in objects, events and acts, I argue that the informants presented here utilize this location in an attempt to progress from their illness experience.

In “The Regimes of Hope”, I argue against much of the self-help literature on stroke, which promotes positive thinking to such a degree that it may be experienced as instituting a regime of hope. Hope thus features as a forced location after stroke; of having to hope when there is no hope in sight, and of being forced to deal with the brand of having a bad morale; e.g. not fighting enough.

“This “Other” Brain of Mine” represents a return to the theme of location, albeit not specifically the location of fatigue. Rather, it examines the way in which the notion of “self” may become crucial when a stroke affecting the brain separates the brain from the self, thus making the brain appear as an “Other”. The chapter explores the location of the self, and how this location is essential in managing one’s everyday life after stroke. Finally, the last chapter “A Question of Location” sums up as well as expands upon the concept of location and its use in the study of experiences, pointing towards future perspectives for social-scientific studies on life with fatigue after stroke.

As mentioned in the beginning, several routes have been travelled in the process of writing the thesis. This thesis represents one possible route of several. Hopefully, the reader will

find that – unlike reading a defaced and confusing map – the description of the route that I have taken in this thesis is as interesting as I found it to be while travelling it.

Introducing Fatigue through Acedia and Neurasthenia

Fatigue occupies a considerable space in contemporary society. In medical terminology, fatigue acts as a tricky diagnostic tool: it is a symptom of certain diseases, an indication of others and a disease in and of itself – a fact that is particularly obvious with the official diagnosis of chronic fatigue syndrome (CFS) (Organization 1992). Although an individual's experience of fatigue in contemporary society tends to be mentioned as either physical or mental, the highly osmotic relationship between the two categorisations presents a blurry picture of the exact biomedical location of fatigue. Along with dichotomous judgments about the nature of the experience as either normal or pathological, moral or immoral, fatigue enters our lives as both signifier and signified. From a social-scientific perspective, however, fatigue is a negotiable experience and, like any experience, it is experienced in and through its time. In this historical overview, my investigation centres on how fatigue could become an experienceable location and how this location worked in tandem with categorizations of normal or pathological, moral or immoral. In effect, I attempt to illustrate how fatigue has become associated with morals and pathology through the analysis of two conditions: acedia (300 AD) and neurasthenia (1864 AD); two conditions that emphasized fatigue as one of the predominant symptoms. This chapter provides the background for the empirical findings presented later in the thesis, and is to be viewed both as a complement to the forthcoming analysis of my empirical material, as well as as an example of how the concept of location may be used as a methodological tool in cultural historical analyses.

Following the theoretically genealogical approach of both Friedrich Nietzsche and Michel Foucault in “Nietzsche, Genealogy, History” (Foucault 1977) and *The Will to Power* (Nietzsche 2006 [1906]), I suggest examining instances wherein the phenomenon of fatigue discursively emerges in relation to the construction of these two conditions, as well as the circumstances under which it emerges. In that sense, a diagnosis of either acedia or neurasthenia represents a particular point in time during which fatigue was negotiated. A genealogical approach allows me to investigate the conditions without claiming to look for an origin that grounds the phenomenon of fatigue; instead, I analyse each specific condition in relation to its occurrence in time and space, and thereby facilitate the construction of an image of how society has dealt with the location of fatigue. In essence,

there is nothing teleological about studying the location of the phenomenon of fatigue from a genealogical perspective; rather, it is plagued by contingency, and contingency is exactly what structures notions of fatigue as a constant matter of location.

According to medical historian Charles Rosenberg, disease is:

...at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine's intellectual and institutional history, an aspect of and potential legitimization for public policy, a potentially defining element of social role, a sanction for cultural norms, and a structuring element in doctor/patient interactions. In some way disease does not exist until we have agreed that it does – by perceiving, naming, and responding to it. (Rosenberg 1989, 1)

Although I much prefer the use of the word *conditions* when referring to acedia and neurasthenia, Rosenberg's description of disease is wonderfully apt as a pre-advanced indication of some of the issues that I look into in the following chapter. Being a socially interactive yet elusive entity of negotiation, the term 'disease' expresses the difficulty of categorising experience. From an analytical point of view, one can attempt to separate the *ontological* from the *physiological* – e.g., as done by historian Owsei Temkin (Temkin 2006 [1977]). In Temkin's terminology, the ontological refers to the existence of disease in and of itself, and the physiological connects a disease to the individual being diseased. Or, as Arthur Kleinman famously argued, there is a distinction between disease and illness – illness is the patient's experience, and disease is the medical view (Kleinman 1988a). In effect, a synthesis of the perspectives of both Kleinman and Temkin would argue that humans do not experience a disease in a one-to-one relation to the medical description of that disease; instead, we experience it as mediated through our situated bodies. The fact that disease is social is most clearly expressed in nosology, which facilitates the rationalisation, mediation and legitimisation of relationships between individuals and institutions (Rosenberg 1992, 316). As Rosenberg argues, this naming and accompanying diagnosis constitutes disease as a social phenomenon; without this, it would not exist. As historians Dorothy Porter and Roy Porter argue, the translation of personal experiences into communication follows the Wittgensteinian axiom of the inexistence of private language (Porter and Porter 1988, 9). Following this line of thinking, it is fair to say that disease and diagnosis serve as a monitory comment on society; a comment that places the *real* in opposition to the *ideal* and, in doing so, creates a rationale for social action.

The fact that disease is social also means that, although a disease may seem to have a somatic individuality, it is always experienced in a cultural and historical setting (Rosenberg 2003, 494-495). Applying Rosenberg's logic of disease in relation to the conditions of acedia and neurasthenia, I propose to look at the locatable experience of fatigue within these conditions. In order to argue how acedia and neurasthenia may have been experienced in the past, the following section briefly presents a general existentialist-phenomenological view of the experience of conditions in history. This is done to provide the reader with an understanding of fatigue as a lived phenomenon – bridging the gap between the genealogical approach that emphasises emergent discourses, and the experienced life in which these discourses occurred; i.e., how a condition may be experienced as a condition, and how the location of fatigue within the condition is part of constructing the experience. The phenomenological viewpoint also complements the existentialist-phenomenological approach that characterises the second part of this thesis: much of my analysis being informed by an existentialist-phenomenological analysis of the experiences of life after stroke.

The Experience of a Condition

In order to position the aforementioned phenomenological approach, I take a slight detour here to present Heidegger's concept of being.

Heidegger's principal statement was that, in order to understand being, we must begin our search *in-being*. Implicit to this statement is a critique of the heretofore traditional philosophical focus on consciousness as something that rises from the world (the naturalist argument) or that the world is constituted by a consciousness (the idealist viewpoint) (Safranski 1998, 175). To begin with in-being does not suggest experiencing oneself and thereupon the world, or vice versa; rather, it is being able to take note of the fact that the connection between the two is mutually and simultaneously given. This is what Heidegger, with reference to Husserl, calls 'intentionality' – it is the *Dasein's* relation to the world. In this way, our being in the world expresses our *Dasein* as something that is not opposite the world – i.e., against the world – but as something that is always already engaged in it (Safranski 1998, 176). The innumeral *beings*, Heidegger inculcates his nouns with in *Sein*

und Zeit (Heidegger 1962 [1927]-b), thus demonstrates his continual attempt to move beyond both naturalism and idealism, as well as to show how in-being is a way of allowing the phenomenon to display itself – to essentially allow the intentional phenomenon to emerge. As Harman argues, a Heideggerian intentional phenomenon or object is always split; it is something *more* than what it appears to be while it is also something *less*:

The tree as an *intentional* object is not a real object growing and nourishing itself in the outer world, given at any moment to consciousness. While the real tree is always something *more* than whatever I see of it, the intentional tree is always something *less*. (Harman 2010, 204)

This means that an object or a phenomenon is always seen specifically; e.g., in a certain mood or from a certain angle. Changing these aspects – moods or angles – does not change the object as an intentional object, which remains a specific unit for as long as I acknowledge it as such. It is the *as-structure*⁷ that Heidegger, in further development from Husserl, continuously emphasises as being the possibility of understanding the phenomenon as something in particular. In the preface to the Danish edition of “Was ist Metafysik” (Heidegger 1999 [1929]), philosopher Jørgen Hass describes it as such:

According to Husserl, every phenomenon appears to consciousness in an “intentional horizon”, also called a horizon of meaning (Sinnhorizont); i.e., a phenomenon shows itself as a sign (Zeichen), as the “carrier” of a meaning.⁸ (Heidegger 1999 [1929], 28)

The experiential part of the phenomenon’s appearance hereby becomes a specific experience that is dependent on the consciousness of an individual, while a reduction of the phenomenon into a certain meaning reveals a pattern. Heidegger argues that this pattern might be able to tell us what the *being* of the phenomenon is, as this pattern allows us to identify the perception. Referring to Jørgen Hass once more:

To identify something is to “see” something *as* something. To see a ball as a ball is to disregard everything that is unnecessary for the “pure” phenomenon (the *eidos* of the ball or pure gestalt); e.g., its size, colour, weight, material, movement, etc. What remains – the “phenomenological residue” – is a specific structure. In this case, it is a definite relation between an object and the space it occupies: the ball is an object with a surface whereupon any point is the same distance from a fixed

⁷ This is my translation of Danish scholar Jørgen Hass’ translation from the German *Als-struktur* to the Danish *Som-struktur*; it should not be confused with Graham Harman’s use of the term, although they are somewhat similar.

⁸ My own translation. The original text is as follows: *Ifølge Husserls fremtræder ethvert fænomen for bevidstheden i en ”intentional horisont” også kaldet betydningshorisont (Sinnhorizont), dvs. et fænomen viser sig som et tegn (Zeichen), som ”bærer” af en betydning* (Heidegger 1999 [1929], 28)

point. Here, a network of “meanings” (“point”, “surface”, “object” and thus “space” are united, and thereby constitute the “meaning” that the phenomenon of the ball signifies.)⁹ (Heidegger 1999 [1929], 28)

In other words, any phenomenon is something that appears in a specific way within a “horizon of meanings”. This way of thinking could easily be mistaken with the positivist view of observation, yet the great divide between positivism and Heidegger’s phenomenology is best exemplified by Husserl’s analogy of the forest. From a phenomenological point of view, we always see a forest firsthand. We do not see some objects that can be identified as trees, only to reduce them to a forest with trees (ibid.: 29). In this way, Heidegger returns to the circularity of the argument when he says that we are always in-being, and this in-being is signified by a constant interaction with the world, and – most often, a specific interaction with something. At the same time, it is important to keep the distinction from Husserl – as explicated in the introduction – in mind; namely, that there is no such thing as presuppositionless experience and that a phenomenological reduction is impossible.

It is in this context that we always already experience a condition as something that relates to our partaking in/being-in-the-world. Unlike the Cartesian subject, we cannot separate our senses from the mind, but are embodied subjects in the world. When a condition is written into our intentional relation to the world, it presents itself as such. We cannot necessarily separate the experience of a bodily phenomenon from that of a condition; instead, we are obliged to view it from the framework within which it is experienced. To that extent, the experience of a condition is in a constant negotiation with how the condition is perceived in the world. Facilitated by our being-in-the-world, we become attuned to identify when our experiences might relate to certain conditions, and we receive a language for speaking about and relating to these conditions.

⁹ My own translation. The original text is as follows: *At identificere er netop at ”se” noget som noget. At se en kugle som en kugle er at se bort fra alt det, som er uvæsentligt for det ”rene” fænomen (kuglens eidos eller rene gestalt), for eksempel den størrelse, farve, vægt, materiale, bevægelse osv. Hvad der derved bliver tilbage – de ”fænomenologiske residuum” er en bestemt struktur, i dette tilfælde en bestemt relation mellem en genstand og det rum den indtager: kuglen er et legeme, på hvis overflade ethvert punkt har samme afstand fra et fast punkt. Her knyttes et net af ”betydninger” (”punkt”, ”flade”, ”afstand”, ”legeme” og dermed ”rum”) sammen og konstituerer derved den ”betydning”, som fænomenet kugle betegner* (Heidegger 1999 [1929], 28)

The diagnosis of a condition attaches meaning to the experience and, in doing so, transforms the experience to something specific. In short, a diagnosis reduces the plurality of any experience to something particular. The diagnosis thereby constructs a specific explanation that transforms into one's lived being-in-the-world; in other words, a diagnosis 'recognises' the experience as something particular. A diagnosis gives meaning to the experience by locating the experience within the diagnosis itself; this not only assures the individual that he/she is not alone in the experiences of the condition, but it also facilitates a more general 'mapping' of the body that can be utilised to determine a prognosis. In other words, a diagnosis in and of itself contains a potential risk, which can be seen in connection to the range of other bodies with a similar diagnosis (Beck 1992, 52). As Roland Barthes argues in his short paper "Semiology and Medicine" (Barthes 1988), the physician's discourse transforms the symptom into a sign and being such a sign, it is "anamnestic it says what has happened; it is prognostic, it says what will happen; and it is diagnostic, it says what is happening" (Barthes 1988, 204). Thus, from a semiological point of view, fatigue is defined when being a sign within the context of a diagnosed disease. Fatigue as a sign of the disease takes on a specific character within every disease, being structured by the disease; i.e. the degree of fatigue, the prevalence of fatigue as opposed to other signs etc. In essence fatigue, in medical semiology – besides being a diagnosis in itself with CFS – is defined by its location within a diagnosis. As Foucault argued in *The Birth of the Clinic*, by the 18th century the medical sign replaced symptoms by transforming the bouquet of symptoms into a sign, which meant that disease was simply a collection of symptoms, observable to the clinical gaze (Foucault 2003 [1963]) In effect, the diagnosis is a specific construction of a condition that transforms experiences by narrowing them down. Physician and literary scholar Rita Charon argues that:

Medical case histories conceptually enclose narration, constrain signs to mean only one thing, and tie utterances down to unalterable meanings, whereas patients' narratives improvise, recombine dissimilar elements, go somewhere without knowing where they are going, and open possibilities (Charon 1992, 118)

Within the framework of location as explored in this thesis, what Charon and Barthes essentially point to is how a diagnosis presents an attempt at monopolizing the location. Something which – as should become obvious later in the thesis – is difficult to do.

From a cultural-analytical standpoint, the existentialist–phenomenological approach outlined here may seem to have a disproportionate emphasis on the individual experience of fatigue, while it misses a societal perspective or at least makes the societal perspective a minor part of the puzzle. This overarching critique of phenomenology is well-grounded and well-founded, and it addresses one of the biggest challenges to applying phenomenology within cultural analysis. Nonetheless, I argue that a phenomenological perspective of history, combined with a genealogical approach, is a way to avoid both essentialisms and universalisms. With the genealogical approach, it becomes obvious that an essence never existed beneath the experience; with the phenomenological approach, the experience is presented in an intentional horizon of possibilities rather than as a single possibility. I claim that the two approaches together best elucidate how the locations of fatigue within the conditions are part of structuring the experience¹⁰.

Fatigue and Acedia

When a conversation turns to the subject of fatigue, *acedia* is probably not the first word that comes to mind. In spite of this, studying the history of a condition like acedia provides us with a general idea about different understandings of fatigue from the early Christian era to the early Renaissance. To clarify, acedia is *not* another word for fatigue, but it is a somewhat diffuse physical and spiritual condition, wherein fatigue features as an essential aspect. For the intents and purposes of the present thesis, my approach to acedia is as a condition that located fatigue. The following outline thus serves to show how the condition located fatigue, and how the condition was defined within the context of contemporaneous society.

Scholars like Julia Kristeva and Walter Benjamin have interpreted acedia as a kind of melancholia (Kristeva 1987; (Benjamin 2003, 155), professor of French Reinhardt Kuhn (Kuhn 1976) has interpreted it as similar to ennui (Toohey 1990, 339) and philosopher Giorgio Agamben compares it with a “mortal illness containing in itself the possibility of its own cure” (Agamben 1993, 7). In all these interpretations, fatigue is merely a *symptom*. Thus, the presentation of acedia that follows includes the history of a condition as well as a

¹⁰ That being said the chapter that follows is more genealogical than phenomenological in nature. This is due to the fact that I have not included personal accounts, such as biographies, etc., in this section.

word. As Siegfried Wenzel, author of *The Sin of Sloth: Acedia in Medieval Thought and Literature* (probably the most thorough overview of the history of acedia), writes in his preface:

... the chapters that follow deal primarily with the meaning of a word. Yet they are more than a purely semantic study, inasmuch as the history of acedia was intimately connected with and dependent upon, the milieu in which the term was meaningfully employed, becoming itself molded by larger changes in doctrine, intellectual as well as practical preoccupations, and society. (Wenzel 1967, vii)

In the overall framework of this thesis, the history of acedia exemplifies the intricate relation between fatigue, morality and pathology. It highlights how fatigue was entangled in this relation, and it shows how the definition of – as well as the cure for – the condition was dependent on who was, and who could, become ill. In essence, the history of the condition of acedia touches upon the issue of fatigue as a located experience, structured around specific historical and social circumstances.

The word *acedia* had different usages in classic Greek literature, where it was used to describe either carelessness, lack of sorrow, weariness, exhaustion or apathy (Wenzel 1967, 6). But a more precise use of the word is not found until the early Christian era (dating back to the 4th century AD) when Evagrius Ponticus, a hermit who lived in the deserts close to Alexandria, Egypt, recorded the first Christian-era use of the word. In *Praktikos* (Evagrius 1970 [382-399]), Evagrius described what he termed “noonday ἀκηδία (acedia)”; also known as the ‘noonday demon’ and later as ‘the demon of noontide’. The demon’s primary feature was its ability to strike the monks when the sun reached its zenith and, in doing so, it incited a sense of immobility of time and dissatisfaction with one’s current circumstances in life (Agamben 1993, 3). Evagrius saw this ‘demonic’ incitement as something that caused the monks to give in to sleep or leave their cells, which could eventually result in them abandoning their spiritual and ascetic lives in the desert. However, while Evagrius described acedia as one of the most dangerous temptations, overcoming ‘the demon of noontide’ held an equivalent reward. As depicted by Evagrius, it was only possible to conquer acedia through a combination of patience and endurance in spiritual endeavours and physical labour (Wenzel 1967, 5-6). In other descriptions in the years that followed, acedia remained a vice for those who lived eremitic lives in the desert, and conceptualisations of the condition did not essentially change.

Instead, a change occurred when Evagrius' pupil John Cassian, in his series of books, *De Institutis Coenobiorum*, wrote about his experiences with monastic life in Palestine and Egypt. Here he identified and described acedia as a weariness or distress of the heart. For Cassian, the cure was similar to the one Evagrius reported; however, in discussing acedia along with eight other chief vices, Cassian carefully constructed certain virtues to act as counterparts to the vices. In the case of acedia, the virtue was *fortitudo* (strength). As such, Cassian's biggest achievement is arguably how he mapped the vices in relation to certain virtues, as well as mapping connections between the vices – one vice leading to another and so forth – thus outlining which vices were responsible for others. In Cassian's scheme, this meant that acedia was the primary vice from which arose idleness, somnolence, rudeness, restlessness, wandering, instability of mind and body, chattering and inquisitiveness. However, among the chief vices, acedia was described as exclusive to the *hominis religiosi* living cenobitic lives (Wenzel 1967, 20-21; Agamben 1993). As mentioned, Cassian proposed remedies that were similar to Evagrius'; e.g., to keep to one's cell. But in his second book, *Instituta*, Cassian espoused only manual labour as a cure (Cassian 2000 [420]) – Wenzel attributes this to the fact that *Instituta* was written to regulate the external circumstances of monastic life in Marseille, which was more community-orientated than the hermetic life of those in the desert, and which left little space for idleness (Wenzel 1967, 22). This seems to propose that acedia was gradually transforming from being a vice relating to hermits to becoming an increasingly social vice of regulation.

When Gregory the Great became pope in 590 AD, a new series of chief vices came to dominate – in a sense, they could be seen as leaving acedia out in the cold, as it would temporarily no longer figure as one of the now seven vices. Acedia was replaced by a new vice: *tristitia* (sorrow), a condition that Cassian had also included as a vice, but which had figured as separate from acedia. One might ask why it is important then to include the interpretation of *tristitia*, if it leaves acedia out of the picture. The answer to this question is multifaceted. First of all, as a chief vice described by Gregory the Great, *tristitia* had a number of other vices connected to it (which was also true of acedia, according to Cassian's description). Secondly, as I discuss later, *tristitia* came to be important in subsequent descriptions of acedia. Whether or not Gregory the Great knew about acedia is

unknown, but Dom Robert Gillett speculates that either Gregory did not know about acedia at all (Wenzel 1967, 25), or else that he understood the pathological character of acedia, seeing it as beyond morals. Wenzel, on the other hand, speculates that, because acedia was framed in relation to the hermetic desert monks living in Palestine and Egypt in particular, *tristitia* was targeted at the Benedictine monks' way of life in the eastern part of the European continent. Their way of life was characterised less by autonomy, hermeticism and individual responsibility towards God, and more by responsibility towards the abbot, following a strictly regulated discipline as proscribed by the head of the monastery; this statement is supported by Dom Robert Gillett, who argues that Gregory the Great considered a mixture of apostolic ministry and humble devotion to God to be the highest service, as opposed to the hermetic life of the desert fathers (Clark 2003, 96). Moreover, for the Benedictine monks, sleep was considered a basic human requirement, whereas it was portrayed as a necessary evil to the desert fathers (Wenzel 1967, 27). This demonstrates how a development of *tristitia* in the West focused more on the welfare of the community than on the individual – i.e., a person's inability to work due to lack of sleep would cause problems for the entire community.

There are numerous arguments as to why *tristitia* did not completely oust acedia, but most important is that acedia (as described by Cassian) continued to exert its influence amongst the Benedictine monks; by the 11th century, it was mainly understood as the physical phenomenon of idleness, and in the 12th century, it was interpreted as an internal phenomenon of mental slackness (Wenzel 1967, 30). As a good example of the former understanding of acedia, Wenzel quotes Saint Peter Damiani:

The coming of dawn, at which time *acedia* falls upon us more heavily, must find us upright and busy with reciting the Office. (Wenzel 1967, 30)

The 12th-century approach is seen in another quote from Saint Bernard:

Is anyone strongly disturbed, languishing either from some bodily discomfort, from some worldly affliction, or from *acedia* of the spirit and slackness of the mind? (Wenzel 1967, 31)

With utmost clarity, these two quotes illustrate how the term acedia changed from referring to something physical to something spiritual; in some descriptions, such as those given by Isaac de L'Étoile, acedia is defined as a plague that one must be vigilant towards.

Vigilance was prescribed as one of the best ways to prevent acedia and, despite other measures, such as implementing variations in the monks' everyday lives, vigilance remained the best prevention for the 'demon of noontide'. This is in direct opposition to Agamben's contemporary interpretation of acedia in *Stanzas* (Agamben 1993); here, acedia is presented as the prerequisite for eventually attaining an enlightened being. In Agamben's logic, acedia was not only a flight from being, but also an eventual flight *towards* being – similar to, as Agamben himself points out, the concept of despair described by Kierkegaard in *Sickness until Death* (Agamben 1993, 6).

In the Carolingian period lasting from the late eighth century to the ninth century, the vice of acedia had travelled beyond the walls of the monastery to affect laymen scholars. Amongst them, the vice was primarily described as negligence in regard to performing spiritual deeds as well as just plain idleness – i.e., not being occupied in making a profit (Wenzel 1967, 37). The pathological nature of acedia is emphasised in many of the descriptions targeted at handling laymen, and the different Christian catechisms about how to address acedia amongst laymen increasingly focused on the actual physical act of attending Mass or being occupied by work. In other words, acedia could be immediately recognised as a sin and thus punished; it was not merely an individual's inner turmoil and distress over the state of things.

With Scholastic theology and specifically Thomas Aquinas (1225-1274), the vice became more of a spiritual affliction. Aquinas argued that acedia was an aversion to experiencing spiritual good, which translated into *tristitia de spirituali bono*. Here, we see a clear connection between *tristitia* as described by Gregory the Great and the *acedia* of Thomas Aquinas, yet Aquinas contributes to the general understanding of acedia by showing how a person's aversion towards spiritual good may come from the physical labour attached to obtaining this (Aquinas 1999 [1265–1274], 1768). In other words, Aquinas interprets the body's natural state as being inclined towards rest; thus, acedia is a result of the burden of man's flesh. The virtue that would counter the vice, however, was not *fortitudo* as described by Cassian, but was more closely associated with what opposed *tristitia* namely *gaudium* (spiritual joy). In that respect, Aquinas argued that the moral precept was closely related to the Third Commandment, whereby one should rest one's mind in God; thus, for Aquinas,

acedia became a spiritual vice more than anything else. More than being a physical affliction, it was an aversion to what should be man's greatest love – God. In many of the descriptions of acedia that followed Aquinas, acedia is described as a disorientation in one's emotional life (Wenzel 1967, 57).

Whereas the Carolingian period had just only brought the vice of acedia beyond the walls of the monastery, with the Reform movement in 1215, the vice was eventually brought to a wider public. Coupled with a reform the same year that required every Christian to receive communion and make confession at least once a year (Wenzel 1967, 64), acedia increasingly became one of the sins heard during confession and, subsequently, a number of books were published that were aimed at the confessional priests. The confessions of acedia were as diverse as they were numerous, yet the image of acedia as a layman's vice contained some common threads that ran throughout the descriptions. Whereas handbooks from the Carolingian period had provided very particular instructions for how to handle the sin of acedia, handbooks after 1215 focused more on helping individual priests judge the sin and proscribe the necessary means to eliminate it. However, throughout the history of acedia as a layman's disease, the fact remains that acedia was usually measured in terms of *sloth* or *laziness*, and a priest could most easily make the person confessing his sins understand this sin through his own physical deficiency. Therefore, in the handbooks and catechisms, there was an increased focus on acedia as a physical affliction exemplified by sleeping too much and being inactive, and the need to eliminate acedia was furthermore accentuated by the wide range of other vices that began to accompany it. Acedia as *sloth* was accentuated, and the interpretation of sloth could include being negligent in taking care of one's household or having a miscarriage (Wenzel 1967, 70).

The promulgation of sloth as external demonstrates a focus on the body's activities as observable, and acedia became a sign of a deviant body that was not under the control of the individual seeking God. In that respect, it is not very surprising that the layman's virtue that often contrasted sloth was *busyness* – a word that is easy to separate from Cassian's *fortitudo* or Aquinas' spiritual joy, as it denotes constant activity as a goal in and of itself. This could be further stressed by a phrase found in the Old Testament, "*Man is born to*

work, and the bird, to fly” (Wenzel 1967, 87), whereby a man who works is doing what God created him to do, and failure to comply with God’s command would be sinful. However, since the time of Cassian, this idea of constantly being at labour had already been framed by the word *otiositas*, which had at times been connected to acedia. But the distinctions between acedia, sloth, *otiositas*, *tristitia*, etc., were gradually fading into a more solitary picture that encapsulated all of the vices related to acedia. Despite the focus on defining acedia as a layman’s condition, Wenzel argues that sloth remained a sin of neglecting religious duties – primarily the less-than-worldly duties – and, in this sense, sloth was the neglect of God, failing to attend Mass or falling asleep in church.

Different assumptions have been made about why acedia vanished, both as a word and a condition. Some speculate that acedia never survived the transition from a vice of the spirit to a vice of the flesh, and thus also the transition from a monastic description to a layman’s term, and it was eventually replaced by sloth. Others speculate that the term was fully incorporated into a range of other words, such as ennui and in fact, acedia had somewhat of a revival in the 18th century with the literary works of Charles Baudelaire (Kuhn 1976, 42), wherein the term was synonymous with ennui. Wenzel argues that the vice finally disappeared during the Renaissance when the seven vices were replaced with an ethical system based on Aristotelian thought and natural philosophy, but also due to the theological flimsiness of the concept of acedia – as opposed to a vice like *envy*, for instance (Wenzel 1967, 91); *Otiositas* and *tristitia*, the two vices for which acedia had been the chief vice, came to be known as ‘laziness’ and ‘melancholy’ during the Renaissance, only to be reunited with acedia three hundred years later by Romantic authors like Mallarmé (Lloyd 2005) and then again by author Aldous Huxley in the 20th century (Huxley 1971),

From this brief outline, it seems that acedia had a number of different meanings and was interpreted in various ways, depending on time and context. But it is clear that the description of the condition of acedia connected fatigue to morality and ultimately pathology. Over the ages, the accepted definition of acedia was constantly on the verge of changing, and the inherent flimsiness of the condition did not do much to prevent this – in fact, the opposite was true. As stated at the beginning of this chapter, Julia Kristeva argues that melancholy has its roots in acedia being a “protestant, orthodox, strict and sad vice”

that might expedite one's ability to obtain divine knowledge (Kristeva 1989, 23). However, Kristeva argues that, with the Aristotelian turn during the Renaissance, acedia becomes a vice of human nature; thus, from an existentialist point of view, it may enlighten a person about the true meaning of being, similar to Kierkegaard's subsequent concept of *Angst*. While not necessarily disputing Kristeva over the historical transformation from Protestant acedia to existentialist Angst, the change nevertheless shows how the condition of acedia is, even today, ripe for adaptation into a wider theoretical and also historical framework¹¹. This does not mean that the concept is inevitably ontological (as in "we have always had Angst, we just called it something else"); rather, it is a concept and a condition that has been constituted based on the relations of which it has been a part. Because acedia, from a contemporary perspective, seems to have been flimsy as both a concept and a condition, it has also been a somewhat empty signifier to be filled by posterity; this accounts for its numerous and often contradictory adaptations within contemporary literature, as previously shown.

The question of whether one can call acedia a disease is difficult – not only because it rings of anachronism, but also because it entails a major study of the relationship between religious vices and actual physical diseases, which would have to reveal a correlation between the vices and their specific contexts. For example, contemporary scientific analyses claim that *stigmata* have their origin in different psychopathological diseases (Fessler 2002), but one must remember that the symptoms of stigmata only existed as long as they belonged to a specific person found eligible for the brand of stigmata; a brand that changed when the word became increasingly used in the 19th century to describe hysteria, degeneration and criminality (Connor 2004, 84). Similarly, we must understand the dynamics that surrounded the emergence of acedia, and how, with fatigue as an essential component of its character, it could mean several things at the same time, depending on who had been caught by 'the demon of noontide': i.e., after being healed from the affliction of acedia, a layman could potentially attain a certain level of the virtue *busyness*, whereas a monk could reach a certain spiritual enlightenment towards God, be it *fortitudo* or *gaudium*. But the fact that the outcome of acedia could be different depending on a

¹¹ The book *Acedia: The Darkness Within (And the Darkness of Climate Change)* was published only recently (Macquarrie 2012). It connects acedia to climate change by arguing that modern acedia is reflected in the constant and scrupulous transformation of the environment to avoid pain.

person's social class does not mean that acedia was not a disease, as many diseases have been believed to target classes differently (a later example could be gout – see Roy Porter and George Rousseau (Porter and Rousseau 1998)). Also, at that time, it is safe to say that the division between religion and medicine was not as clear-cut as it is in contemporary society.

So what can we actually say about the location of fatigue, now that we have looked into the 'flimsy' concept of acedia? First of all, one thing is worth mentioning: fatigue as the word figured in the first French usage in 1669 is not present in the descriptions of acedia, unless the words for listlessness or weariness have later been particularly translated to fatigue. Rather, it is a contemporary reading of descriptions of acedia that has prompted me, as well as French philosopher Jean-Louis Chrétien (Chrétien 1996), to interpret a central feature of the condition of acedia as fatigue. By doing so, I point to an instance in time that presented a description of a condition that we could – from a contemporary point of view – interpret as containing central elements of what we in current terminology would call fatigue. Such an interpretation naturally seems to assume a certain anachronism by the fact that it interprets the condition at a certain point in time. However, this paradox is part and parcel of historical representation, and cannot be avoided (Ankersmit 2001, 151). As famous historian Benedetto Croce stated, “all history is contemporary history” (Trafton 1999), which Professor in English Dain A. Trafton takes to mean that:

... all serious study of the past is informed by the problems and needs of the writer's own time; the more conscious historians are of their contemporary motives, the more searching and accurate their investigations of the past and the more useful their reconstructions. (Trafton 1999, 103)

In effect, the analysis of acedia (as well as neurasthenia) as a condition with fatigue naturally reflects the intents and purposes of this thesis to present the locations of fatigue. Interpreting acedia as a condition that facilitated a location of fatigue as something specific allows me to represent how a location could structure the experience.

In summary, the central point is that *acedia is a condition that locates fatigue*. As illustrated, acedia was a condition that remained dependent on the time and place it was described as well as the worldly status of the person who acquired the condition. Acedia could thus be

primarily a spiritual and/or a physical condition. In the original description by Evagrius, it is a spiritual condition that manifests itself in a lack of physical activity as well as potential loss of faith. The location of fatigue in this instance is first and foremost the demon of noontide. This demon that caused all of the afflictions of acedia, previously mentioned, is a strange character. In *Demons and the Making of the Monk: Spiritual Combat in Early Christianity* (Brakke 2006) by historian David Brakke he points to the influence on Evagrius by the early Christian theologian Origen who associated demons with thoughts (Brakke 2006, 12-13). As Origen argued, sometimes these evil thoughts, of which Evagrius would list eight of them as primary, could come from oneself or from a demon. When these thoughts eventually came from oneself, it was due to the fact that one had been corrupted by the demons for a sufficiently long period of time, which made it impossible to resist the thoughts. Seen from this perspective, one could thus argue that the fatigue of acedia was located in thoughts as much as in demons. The demons might incite the thoughts but eventually it was up to oneself to repudiate the demonic presence. Evagrius' description of acedia would thus point quite specifically to an individual and spiritual resistance to fatigue. Acedia would place fatigue within a larger framework of a struggle against the incitements of demons. Whereas Evagrius imagined the individual and spiritual resistance against the demons as part of a greater fight against demons, Cassian would make it even more individual by arguing that the monk's conflict with demons was a constant, divinely planned affair within himself (Brakke 2006, 244). Cassian's focus on a divide between man's pleasure-seeking flesh and his spirit of free will essentially made the flesh the gateway for demonic incitement, and fatigue would be located in a sinful body succumbing to the pleasures of the flesh (ibid.). The disciplining of the body through manual labour, which Cassian proposed to counter acedia, was thus in keeping with this notion of the sinful flesh. As Brakke argues throughout *Demons and the Making of the Monk*, evil forces played a large part in the formation of the monk as a virtuous self and as a social role (Brakke 2006), and the location of fatigue within acedia came to align fatigue with an evil presence. In essence, the location of fatigue within acedia accounted for a specific construction of fatigue that would make it a question of faith and morals among the monks living a monastic life. The description of acedia by Thomas Aquinas, which came more or less at the same time that acedia was becoming more of a laymen's vice, could be said to hold on to acedia as a monastic vice. As a layman's vice, acedia was

increasingly portrayed as a physical affliction of fatigue and laziness. Historian Anson Rabinach argues that, in addition to laziness and physical weariness, the lack of a time sense that followed with acedia as a laymen's vice was in large part portrayed as the biggest of problems with acedia, as it did not fit in with maintaining "a regular time bound sense of discipline and labor" (Rabinach 1992, 26). As a laymen's vice we thus see the obvious distinction from the first description by Evagrius of acedia being less of a spiritual struggle against a demon, or the spirit of Cassian struggling with the flesh, as much as a disorderly condition to the communal organization of a temporal regularity of work (Johnsen 2009, 101). This definition of acedia would thus locate fatigue as a symptom of idleness, only to be dealt with through more work.

In the earliest descriptions, manual labour had been a remedy for acedia for the monks, but later, a laymen body not at work was a sign of acedia – and this inversion is particularly interesting. The movement from a treatment method to a symptom illuminates the circumstances in which acedia was introduced and translated into layman's terms. As a layman's vice, it gave society a certain order with which laymen could be disciplined to attend church and not fall asleep during services. In other words, acedia clearly consolidated the power and voice of the Church, and experiencing fatigue while attending a sermon was interpreted as acedia – the demon of noontide – which prevented one from hearing the word of God.

In that sense, it is also difficult to argue that fatigue became pathological; nevertheless, it is fair to say that fatigue as a symptom of acedia did present a moral, metaphysical and pathological conundrum. Acedia shifted from being disorderly and prompting the desert fathers to leave the Church; to being disorderly within the large community of the monastery, where people were dependent on each other's work to provide food, etc.; to being disorderly in society at large; preventing laymen from having a proper relationship to God and thus had the potential to undermine the Church's authority, as well as it threatened to break with the temporal organization of work.

In conclusion, acedia has taken many shapes throughout time. In some cases, it has had the figurative shape of a demon while, in others, it has been seen as the result of physically

harsh conditions or as a spiritual, almost existential, affliction – some historical descriptions are surprisingly similar to contemporary descriptions of clinical depression. It is exactly this amalgamation of the physical and the spiritual that demonstrates the difficulty in separating the body from the mind. The same problem is seen with fatigue, such as when contemporary diagnostics focus on locating fatigue. Questions like, “Where is the fatigue?” (e.g., in the muscles, in the brain (depression), in one’s life) are not merely questions that have gained importance since Cartesian dualism was introduced into Western thought (Crossley 2001). Rather, this trend is intrinsically connected to a way of interpreting something that is posed, or poses itself, as a problem. Thus, when studying the sudden rise of neurasthenia in the 19th century, it becomes apparent that a post-Cartesian interpretation of diseases can be similar to how a sin like acedia was interpreted.

Neurasthenia and Fatigue

The term *neurasthenia* is perhaps better known than *acedia*. Whereas many historians would oppose labelling acedia as a disease, neurasthenia was truly ‘the’ diagnosis of the late-19th century, and it swept through Europe like a firestorm – a firestorm that lasted until 1927 in the West (the term is still used in parts of Asia today; see (Kleinman 1988b). The question of who was the first to coin the term ‘neurasthenia’ still remains unclear, but there is no doubt about who facilitated the widespread use and definition of the word: it is widely attributed to 19th-century physician George Miller Beard (Beard 1971 [1880], Introduction 2a-2b). In his 1869 paper “Neurasthenia, or Nervous Exhaustion”, Beard argued that neurasthenia was becoming increasingly prevalent as a disease in modern American society; Beard later expanded upon this idea in his (at the time) highly influential book, *American Nervousness* (Beard 1881). According to Roy Porter, Beard’s conceptualisation of neurasthenia owed something to the Brunonian system of medicine, whereby diseases could be split into categories of *-sthenia* and *-asthenia* – the latter were caused by an inability to react to stimulus, and the former by an overreaction to stimulus (Porter 2001, 39). Thus, neurasthenia encompassed a range of symptoms that were heretofore contained in other diagnoses. Symptoms of neurasthenia could be: *despair*, *phobia*, *insomnia*, *nightmares*, *inattention*, *migraine*, *palpitations*, *indigestion*, *impotence*, *neuralgia*, *extreme fatigue* and many more. In effect, neurasthenia was somewhat of an umbrella diagnosis that encapsulated many of the symptoms that were being reported by the upper class of

American society. But for Beard, neurasthenia was not merely a regular stigmatic disease (ibid.). Instead, he believed that neurasthenia, being particular to American society, was caused by the innovations of American industrialisation, which had reached the highest levels of civilisation known to this point. These innovations were: *steam power, the periodical press, the telegraph, the sciences and the mental activity of women* (Lutz 1991, 4). As such, neurasthenia was a condition related to overuse of nerve force and, in that sense, it complemented certain contemporary physical theories about the limited amount of energy within systems. Historian Anson Rabinbach argues that, to a certain degree, German physicist Herman Von Helmholtz's 'discovery' of thermodynamics in 1847 contributed to this idea of a universal law regarding the conservation of energy within the human body (Rabinbach 1992, 3). In his first thermodynamic law, Helmholtz proposed that energy is cosmological and, as such, it is a universal force that cannot be added to or destroyed because the cosmos must continuously contain the same amount of energy – an energy that cannot dissipate beyond the cosmos. This thermodynamic law would eventually align the human body with the machine, in the sense that the productivity of both was regulated by energy output. However, Helmholtz's second thermodynamic law described how the transition of energy from one state to another (e.g., from cold to warm) in a closed system always entails the loss of energy. Thus, Rabinbach claims that:

The great discoveries of nineteenth-century physics led, therefore, not only to the assumption of a universal energy, but also to the inevitability of decline, dissolution, and exhaustion. Accompanying the discovery of energy conservation and entropy was the endemic disorder of fatigue – the most evident and persistent reminder of the body's intractable resistance to unlimited progress and productivity. Fatigue became the permanent nemesis of an industrializing Europe. (Rabinbach 1992, 3-4)

But as Porter shows, what could be considered a forerunner to neurasthenia had already been established before Helmholtz's and Beard's thermodynamic and neurasthenic theories, respectively. As mentioned, the Brunonian idea had touched upon the dissipation and excess of stimulation to a certain extent, but the idea of overusing nerves and the possible connection to society came to the fore during the Georgian era with George Cheyne and his diagnosis of *the 'English Malady'* (Cheyne 1991 [1733]). Cheyne coined the term in the 1730s at a time when an increasingly important question was whether "the wealth of nations also gave way for the health of nations" (Porter 2001, 32). Cheyne's

argument was that both the Enlightenment and growing wealth among the upper-classes had created a deterioration of health; thus, without a twist of irony, Cheyne proposed that those in society who were suffering the most were, in truth, people with the highest education and living standards. More than labourers, the elite had to constantly use their nerves and would do so for noble purposes that enhanced civilisation – for instance, business, pleasure, ease and fashion (Porter 2001, 34). However, this ‘disease of civilisation’ did not mean that Cheyne proposed to prevent the progress of civilization that he believed caused the English Malady; rather, he wanted to refine civilisation to aid the suffering upper classes. From accounts of the English Malady, it is quite obvious that the ailment had somewhat of a mark of honour – very similar to what was later seen with neurasthenia. However, compared to neurasthenia and the idea of limiting energy output, the English Malady focused much more on limiting the use of nerves. It was not the substance (energy) passing through the nerves that was the problem, but rather use, and specifically overuse, of the nerves; it was believed that strain on the nerves themselves would eventually render them sluggish.

The theory of entropy, which both Porter and Rabinbach highlight as being crucial in the development of neurasthenia as a diagnosis, was also tainted by an obvious economic metaphor, facilitating the use of the term *nervous economy*. Naturally, people in possession of such an economy would have to balance their expenditures while simultaneously ensuring societal progress – in short, it was a question of investment and having a strict nervous economy (Lutz 1991, 3). This nervous economy was essentially extremely moral, as Beard argued that masturbation, gambling and illicit sexual or financial activity was a waste of nervous energy, while productive work and procreation were valuable reinvestments (Lutz 1991, 3). In Beard’s construction of a moral incentive for work, one can hear echoes of the Protestant work ethic described by Max Weber in *The Protestant Ethic and the Spirit of Capitalism* (Weber 2002 [1905]). But as seen in several other cases, morality and disease were not – and still are not – two separate logics, but were intertwined¹². Beard’s Protestant moral perspective extended so far that even Catholicism and neurasthenia were portrayed as being incompatible due to the lack of advances in Catholic religious persuasion (Beard 1881, 126).

¹² An unfortunate contemporary example could be AIDS or certain types of cancer, wherein the disease is associated with a lifestyle that is portrayed as morally corrupt (e.g., promiscuity, obesity, smoking, etc.).

Overall, and as seen from the hegemonic perspective of Antonio Gramsci (Gramsci 2010 [1950]), neurasthenia did become a diagnosis that supported the ruling classes, as did the English Malady, although the ruling class at this point in time was less aristocratic. To that extent, the problem of maintaining the diagnosis as a mark of honour eventually led to its downfall – it became a victim of the “trickledown effect” (Porter 2001, 32). But the fact that neurasthenia was increasingly common among the elite during the mid-19th century is obvious from a glimpse at the long list of prominent people who received the diagnosis: *Theodore Roosevelt, Eliphalet Remington, Thorstein Veblen, Virginia Woolf, Friedrich Chopin, Silas Weir Mitchell* and *Beard* himself – to mention just a few. Both the cultural elite as well as the political elite were affected by neurasthenia, and the diagnosis provided a somatic cause for an illness that attached a rather benign stigma to those affected; this is comparable to Susan Sontag’s analysis of tuberculosis, which was less stigmatized than a range of other contemporaneous diseases (Sontag 1979)

To return to the metaphor of a nervous economy, it is clear how neurasthenia could offer a medical explanation (i.e., fatigue) for the changes that were regularly occurring amongst individuals in modern society. But the economic perspective, whereby it was necessary to invest one’s resources wisely, was certainly not exclusive to the expenditure of *nervous* energies. Instead, discussions about how to utilise energy and avoid fatigue in relation to manual labour became of greater importance. Ever since Descartes introduced the now-infamous divide between mind and body – the mind being a metaphysical substance with its primary location in the pineal gland, and the body getting the role of an automaton – the body had increasingly been seen as a machine, with the mind as the defining feature that separated man from animals. However, with the growth of industrialisation, the construction of machinery, which recognised the body’s mechanical function, also emphasised the human body as a productive force, or rather as *labour power*. In this way, the actions of the body were not to be seen so much as governed by the mind as by their interrelationship with the machine. According to Marx, this interrelationship was so skewed that, in factory work, the machine makes use of the human worker (Marx 1976 [1867], 548) – something that Marx would later examine in more depth through his concept of Alienation. However, Marx suggests another understanding of the use of

nervous energy when he says: “Factory work exhausts the nervous system to the uttermost” (Marx 1976 [1867], 548).

Within his theory of historical materialism, Marx had incorporated the idea of nervous energy and had included the worker as being in possession of such. Whether Marx would have called the worker ‘neurasthenic’ is an unanswered question, but it goes to show how the idea of nervous energy – and the management of nervous energy – had become increasingly consolidated in society at the time. And energy remained Janus-faced, becoming a point of fascination for several ideological factions of society – from Bolshevism, Fascism and Liberalism to Taylorist capitalism – that proposed making progress through the productive use of energy, while energy at the same time was the limit of productivity (Rabinbach 1992, 2). The physical symptom of this potential depletion of nervous energy was fatigue. However, among the workers within these ideologically diverse factions, fatigue as a symptom was not necessarily connected to a physical loss of energy, but could, for instance, in Bolshevik terms, be seen as a product of false consciousness. In the productivity of Taylorist capitalism, it might be the processes that were not utilised to their maximum, etc.

As a concept, neurasthenia developed in a number of different directions – often depending on the cultural appropriation of the concept. Thus, neurasthenia transcended the borders of American society and became widely known throughout Europe (Sengoopta 2001) and, in the preface to the second edition of Beard’s *A Practical Treaty on Nervous Exhaustion (Neurasthenia)*, he writes:

This observation is of value as showing that this malady is not confined to the United States, where it was first systematically described, and where it is certainly far more common than in all the world besides, and that the symptoms, behavior, and clinical history are the same in both countries.
(Beard 1971 [1880], 9-10),

Seeing all of the work being done on neurasthenia in Europe by scholars such as Wilhelm Erb (Beard 1971 [1880]), William Playfair (Sengoopta 2001, 100) and the pioneer of research in hysterics Jean-Martin Charcot (Goetz 2001) seemed to have convinced Beard of the likelihood that the diagnosis could exist in other countries, although he maintained that the diagnosis was primary to the US. In Europe, neurasthenia also came to the

attention of Sigmund Freud, the father of psychoanalysis, and in his paper “Über die Berechtigung, von der Neurasthenie einen bestimmten Symptomenkomplex als ‘Angstneurose’ abzutrennen” (Freud 1953 [1895]) he paved the way for it to be recognised as a psychoneurosis and thus possible to cure through psychoanalytic treatment. But as Tom Lutz rightly points out, neurasthenia as a psychoneurosis existed in parallel with the actual organic neuroses in Freud’s paper. However, historian Edward Shorter argues that this alternative change in cause – from somatic to mental – affected the general status of neurasthenia, making it less absolved of individual responsibility (Shorter 1992, 222). In effect, with the introduction of psychoanalysis, neurasthenia – previously the disease of modern civilisation – became a different disease. As Freud later claimed (perhaps in light of events in Germany at the time) in 1929’s *Civilization and its Discontents*:

We are threatened with suffering from three directions: from our own body, which is doomed to decay and dissolution and which cannot even do without pain and anxiety as warning signals; from the external world, which may rage against us with overwhelming and merciless forces of destruction; and finally from our relations to other men. The suffering which comes from this last source is perhaps more painful to us than any other. (Freud 1962 [1929], 24).

Similar to Beard, Freud argued that advancements in civilisation put critical demands on the human psychic condition, and he claimed that the constant demand for higher and higher rates of production caused severe mental illnesses – not only among the elite, but also among the workers (Freud 1962 [1929]). But as seen in the quote, mental illnesses could also be caused by certain kinds of social interactions and (sexual) repressions, whereby the expressions of an individual were manifested in both mental and somatic diseases. As Friedrich Nietzsche apocalyptically argued, stopping the train of progress was unlikely, and thus fatigue would continue and accelerate (Nietzsche 2006 [1906]). To a large extent, fatigue was seen as an epidemic caused by progress itself, and it threatened – even promised – a social deformation of society.

Historian Thomas Cole has shown how the threat of social deformation through the loss of energy also applied to the concept of ageing, which was becoming an increasingly prevalent issue in society in the late 19th century. Once again, Beard was at the forefront of these discussions about ageing, and he presented the conviction that old age was “an inevitable casualty in the great ‘race of life’” (Cole 1992, 164). As a way to legitimise his

American Nervousness, Beard showed a graph that outlined the relation of age to original work, and explicated that mental and physical power both decline after age 40. As Cole puts it, this view foreshadowed the alliance that would develop between the American medical establishment and industrial capitalist efficiency. From a political point of view, Beard's ideas highlighted the issue that many men who were well above 40 had high positions, which Beard proclaimed to be a kind of tyranny. Although Beard's arguments for his theories may seem slightly distorted – i.e., being based on when people had produced 'original work' during their lifetimes – his views nevertheless seemed to grow in popularity. Beard also reinterpreted certain features that had hitherto been positively associated with old age; for example, moral courage and happiness became conservatism and cowardice. All in all, Beard considered ageing to be a specific neural decline that occurred from age 40 onwards, and this corresponded to popular ideas about energy conservation. According to Beard, a person had to maintain a certain amount of 'nerve force' after age 40 to slow the decline, and old age was the mark of inevitable cerebral disease. As Cole explains, "Beard deserves the dubious distinction of being the first to scientifically legitimate the reduction of human beings to their productive capacities" (Cole 1992, 168). Cole also argues that Beard, along with physician William Osler, were feeding the establishment with a scientific and unsentimental view of the body, whereby human value was measured by productivity:

The important point here is that by 1900, scientific assessments of efficiency and productivity had come to dominate public evaluation of old age (ibid.).

Even the few who dared criticise this conception of old age did so not by arguing against the decline of productivity in old age, but by arguing that one achieved higher spiritual insights with old age. Felix Adler, leader of the New York Ethical Culture Society, took an Existentialist approach to ageing and argued that, while youth and middle age were times of 'doing', old age was a time of 'being' – thus validating the economic worthlessness of later life (Adler 1906). Adler's ideas had little popular appeal, yet this shows how a lack of energy and a decline in productivity had become central concerns in an increasingly industrialised world. Physical deterioration presented a threat to one's own body – but even more so, it threatened the American dream of accumulating limitless health and wealth (Cole 1992, 175).

However, the idea of productivity and energy did not only correspond to maintaining nervous energy in whatever way possible: in some researchers' attempts to prevent ageing from being unproductive, attention was also brought to sexual and cellular energy. For instance, American writer Charles Asbury Stephens (1844-1931) argued that the ageing process occurred at a cellular level and that, by perfecting cellular nutrition and utilising vital energy for cellular restoration, endless rejuvenation could be ensured – i.e., immortality (Stephens 1892). To Stephens, humanity was “chronically tired”, and the weakening of people’s energies was one of the biggest issues in Victorian society. In relation to sexual energy, masturbation was generally thought to drain the body of energy and thus limit the body’s capacity for productivity. Brown Sequard’s ‘Elixir of Life’ prompted an interest in conserving these sexual energies and, with speculation growing about how vital energy was located in the sex glands, the elixir was soon widely produced and sold (Cole 1992, 180). Although the Elixir of Life was likely quackery and was quickly forgotten, the popular belief that energy was located in the sex glands continued to expand at the end of the 19th and beginning of the 20th centuries. Some people went so far as to have the sexual hormones surgically redirected back into their bodies (Cole 1992, 181). In other cases, treatment of the glands was coupled with disciplined eating habits and sleep patterns (Cole 1992, 185). The prevention of ageing through diet and controlled eating habits had already been widely acknowledged in the 19th century when Kellogg and Post introduced their corn flakes in the US – in some ways, this trend was not spectacular, as food consumption had always been an important part of ageing prevention. Yet producing corn flakes with this specific goal in mind was quite ground-breaking. So, when Nobel Prize-winner Élie Metchnikoff suggested that bacteriology could eliminate infectious diseases and thereby most causes of death, he promulgated a discipline of “civilized morality”; this focused on a rational hygiene that, amongst other things, included a strict dietary prescription centred on sour milk. According to Metchnikoff, the lactic bacilli in sour milk and other dairy products could neutralise the toxins produced by harmful bacteria (Cole 1992, 189). Thus, by incorporating these dietary measures along with exercise, one could prevent disease and be productive throughout one’s lifetime; by adhering to these disciplinary guidelines, the problem of retirement pensions and an increasing lifespan with frailty would be avoided. In this way, there would be a difference

between a natural death and a death caused by infectious bacteria: natural death being the end of “healthy old age” (Metchnikoff 2004 [1908]).

What had eventually been the cause for the spread of neurasthenia also became its downfall. In addition to being a diagnosis that had gradually become more widely used in less-elite circles, neurasthenia had always had the problem of being an umbrella diagnosis that sought to explain nearly everything that could not otherwise be measured. As Beard argues in *A Practical Treaty on Nervous Exhaustion (Neurasthenia)*:

First of all the symptoms of neurasthenia are largely of a subjective character, and to one who does not suffer them, appear trifling and unreal; many of them do not appeal directly to the senses of the scientific observer: the physician can only know of their existence through the statements of the patient, or through his conduct. Unlike the existence of surgical and acute inflammatory diseases, the phenomena of which the physician can see and feel, and for the study of which he is little, if at all, dependent on the patient's intelligence or honesty, they do not appeal directly to the eye or ear or touch, and are in fact quite out of the range of all modern appliances to supplement the defect of the senses, as the ophthalmoscope and laryngoscope, or even the spectroscope. (Beard 1971 [1880], 26-27)

This quote shows that neurasthenia had contained the symptoms that seemed inexplicable, and it provided the elite with a diagnosis that confirmed their positions in society as well as the sacrifice of their nervous energy for the sake of society. However, the eventual disappearance of neurasthenia in Western medicine is not necessarily only related to neurasthenia becoming a *gesunkenes Kulturgut*, or to it becoming a psychoneurosis with its hypothetical somatic foundation removed (Sengoopta 2001, 109); rather, it should be connected to a change in doctor–patient relations. According to historian Mathew Thomson, the diagnosis offered medical recognition of the immeasurable ailments that patients experienced as somatic, and this satisfied the elite patients who were *paying* for a medical consultation (Thomson 2001, 79). But when neurasthenia spread down to the lower levels of society, neurasthenia's former mark of honour was at risk. The diagnosis became especially contested after the First World War, when many of the returning soldiers opting to receive state pensions were suddenly diagnosed with neurasthenia (Thomson 2001).

In light of the range of symptoms credited to neurasthenia, it is quite logical that a number of ailments can be traced back to it. It is a prominent feature in the history of diagnoses like shell-shock and its later version, Posttraumatic stress disorder (PTSD) (Shephard 2003). Another frequently-occurring contemporary diagnosis that neurasthenia has become associated with is ‘chronic fatigue syndrome’. The term was first coined in 1988 and, since then, CFS has had somewhat of a baptism of fire. On the one hand, it has been accused of being just another diagnosis invented by medical companies while, on the other hand, it has been the battleground for a range of patients who have sought medical recognition for their ailments (Straus 1991).

In *Social Origins of Stress and Disease: depression, neurasthenia, and pain in modern China* (Kleinman 1988b), psychologist Arthur Kleinman describes how neurasthenia is still recognised in China. According to Lutz, neurasthenia has been so widely accepted in Asian countries because it is not associated with any stigma (Lutz 1991), although Kleinman argues that a stigma is inherently present in the diagnosis in China (Kleinman 1988b). Social anthropologist Vieda Skultans conjures up a very different, albeit extremely interesting, analysis of neurasthenia in a post-Soviet country like Latvia. According to Skultans, neurasthenia came to denote difficulties related to succumbing to political submission, and was thus an issue of false consciousness. From a psychiatric point of view, history could not provide any consolation because, in creating a true consciousness, the timelessness of Socialism was ubiquitous. However neurasthenia became a tool for translating a political threat into a psychiatric language that had the character of dichotomy – false and true consciousness (Skultans 1997, 9).

At this point, the diagnosis of neurasthenia as a matter of dialectics should be obvious. On the one hand, it represented an explanation for paying patients who had symptoms that were hard to integrate into a medical discourse without stigmatisation; and on the other, it allowed doctors to provide a somewhat satisfying diagnosis that was grounded in the ‘energetic’ discourse of the day. In other words, neurasthenia as a disease *made sense*; it was created through the vocabulary and praxis of the time, and it gave an individual a much-desired place in society. But in entering the field of energy, it also became a sign of the limits of progress and the great human costs made in the name of progress. A diagnosis of

neurasthenia highlighted the moral and pathological nature of fatigue while it also located a person's experience of fatigue. I return to this last perspective of location shortly.

A Digression and a Perspective

A Digression

In *The Concepts of Illness, Disease and Morbus*, Kräupl Taylor explains how the age-old distinction between functional disorders and organic diseases is disappearing in nosology. As such, a range of organic diseases are now classified as 'disorders' – a word formerly reserved for functional disorders – while several functional disorders are classified as diseases. The interchangeability between disease and disorder is, however, not absolute; as Kräupl Taylor argues, there remains an element of separation that is related to the old concepts of energy and force. He explains that the notion of *life force* began as something that corresponded to the air we breathe. When life begins, breathing starts and when life ends, breathing stops – in other words, life force is an element that gives and sustains life. Referencing *Genesis* 2:7, "And the Lord God formed man of the dust of the ground, and breathed into his nostrils the breath of life; and man became a living soul" (Publishers 2004), Kräupl Taylor describes how life, soul, breath and mind were connected to each other and related to Christian doctrine; this association also appeared in the ancient Greek and Roman cultures, where *psyche* was originally a Greek word for 'breath', 'spirit' came from the Latin *spirare* (expire) and *anima* was the original Latin word for both 'wind' and 'air' (Kräupl Taylor 1979, 95). The transformations of this life force throughout history are numerous, and the idea of life force played a large part in both animistic and vitalistic doctrines, which related it to energy and, thus, the right and wrong uses of energy and life force. According to the prominent medical researcher of antiquity Galen of Pergamon (AD 129–c.200/c.216), a human being manifested his life force through three kinds of spirits: natural spirits – a product of the liver; vital spirits that were transported to peripheral organs along with the blood; and animal spirits – produced in the brain and flowing through the nerves to the organs, facilitating movement. Animal spirits became a consistent theme in medical thought, albeit with slight nuances; e.g., nervous power, force or energy. The improper deployment of these energies became the word *neuroses*, coined by William Cullen in 1772 (Cullen 1775). Luigi Galvani (1737-1798) argued that two

different forms of organic electric energy existed and, quite eloquently, named one *animal electricity* – the term was later rejected by Alessandro Volta (1745-1827) (Pera 1992). In his description, Galvani argued that this energy was stored in the brain and went through the nerves to muscles, causing them to contract (Kräupl Taylor 1979, 96). A well-known story about electrotherapy was inspired by Galvani's discovery: when Mary Shelley published *Frankenstein: or, The Modern Prometheus* in 1818, it offered a strong indication of society's assumptions regarding the life-giving power of electricity (Shelley 1996 [1818]).

With the notion of life force, we find a natural contrast between having life force and losing life force. Being linked to notions of the spirit or soul, life force was something that one could either lose or show – e.g., “to lose spirit” or “to show spirit”. Often, life force was transformed into something less benign, such as an evil spirit that could sometimes drain the life force. The concept of life force had an essentially multifaceted character that maintained a certain ambiguity in society, being both a destructive and a productive entity – this easily parallels our contemporary conceptions of electricity and force in physics. The 19th-century notions that nervous and mental ‘diseases’ pertained to nervous energy, and could thus be resolved through neuropathological intervention, eventually lost credence among psychiatrists. They had not found any components that related the ‘functional psychiatric morbi’ to the concept of a ‘disease’; instead, they attempted to supplant the word ‘disease’ with the word ‘disorder’. Life force could thereby be separated into disorders and diseases, and contemporary use of these terms is still characterised by disorders relating to psychiatric descriptions (such as personality disorder, attention deficit disorder, post-traumatic stress disorder, etc.) and diseases relating to a physiological condition. However, as stated at the beginning of this chapter, the two words seem to be increasingly interchangeable – but they also represent the interesting connection between disease as a social phenomenon of disorder. With this wordplay in mind, structural anthropologist Mary Douglas's insights into how societies create *order* and administer *disorder* (Douglas 2005 [1966]) provide a particular perspective on how to interpret the role of fatigue in the diagnoses of acedia and neurasthenia.

A Perspective

In what could arguably be called her most famous work, *Purity and Danger* (Douglas 2005 [1966]), Douglas examines the concepts of taboo and pollution. She asserts that taboos are created by society to maintain the classificatory system, reducing social as well as intellectual disorder and forcing people to confront ambiguous things. Pollution – especially dirt – is dealt with in society through the taboo, and the ambiguous nature of whether or not something is polluted is handled within the framework of the classificatory system (Douglas 2005 [1966], xi). However, she argues, these taboos may be revised with a change in the power structures, but they will be revised within a new framework of classification inherently structured around dichotomy. Douglas’s universalist structuralism is apparent here, and she follows Emile Durkheim and Marcel Mauss (Durkheim and Mauss 1903) in arguing that, in order to make order, one needs to be able to classify, and that classifying is a human universal. In that sense, dirt is only ‘dirty’ if it does not fit into the classificatory scheme set forth by society (Douglas 2005 [1966], xviii). But whereas some taboos reinforce the people in power, others prevent the same people from gaining too much power. In essence, taboos ensure order to the extent that they maintain the hegemony of what is defined as dirty – because “dirt is essentially disorder” (Douglas 2005 [1966], 2). To that extent, when we clean or tidy up, we are not only trying to prevent diseases but also to make our environment conform to a certain classificatory scheme. As seen in the following quote, disorder is shunned, but only to the extent that it also has potentiality for new classificatory schemes. In other words, disorder presents endless opportunity:

Granted that disorder spoils pattern, it also provides the material of pattern. Order implies restriction; from all possible materials, a limited selection has been made and from all possible relations a limited set has been used. So disorder by implication is unlimited, no pattern has been realized in it, but its potential for patterning is indefinite. This is why, though we seek to create order, we do not simply condemn disorder. We recognise that it is destructive to existing patterns; also that it has potentiality. It symbolizes both danger and power (Douglas 2005 [1966], 117).

In the following, I highlight how acedia and neurasthenia were managed within society, thus enlightening the reader about how, as a disorderly element of both afflictions, fatigue came to be the subject of considerable attention.

Acedia was first described as a problem for the hermetic monks living in the Egyptian deserts, creating a risk that they might leave the path of God. To a certain extent, acedia could be interpreted as harmful to the scripture of God, and was thus a disorderly element that threatened the authority of the Church. But the intrinsically individualistic descriptions – as well as the idea of acedia being solely related to the hermetic monks living in the desert – negate such an interpretation. However, the later appropriation of the word within Benedictine circles (in reference to monks living in their community) gives a much clearer indication of how acedia represented a bodily phenomenon that was potentially disorderly. Depending on a monk's efforts and work to sustain the community, and in order to ensure that the monk would not leave the Church, acedia was a logical explanation for why some might consider a life outside of the monastery. But with the acceptance of acedia as a general vice that existed beyond the monasteries – and thus, in its re-interpretation and re-configuration into the world and terminology of the layman – acedia assumed another life and faced another logic. In this new world and terminology, the most obvious signs of acedia were highlighted: falling asleep during religious services or failing to attend Mass were presented as signs of acedia, and the 'demon of noontide' was faulted for preventing laymen from hearing the word of God. Acedia promoted sleep when God spoke. To a contemporary scholar of medical disorders, it would be easy to view acedia as a form of depression amongst the solitary desert monks, and as a lack of self-discipline among the laymen in church. This could be supported by the variety of rewards for overcoming acedia that were presented to either the layman or the monk. However, for my purposes, it must suffice that acedia was extremely multifaceted and had to be understood in relation to the individual who committed the sin. In that sense, I refrain from taking an anachronistic stance on which condition acedia could be interpreted as in contemporary nosology. Rather the fact that acedia could be translated into depression, a state of boredom, ennui, etc. at one time or another quite clearly demonstrates how the categorisation of acedia in and of itself provided an ordering principle for what constituted a disorderly phenomenon.

In the case of neurasthenia, it could be argued that the diagnosis also provided an ordering principle for something that was seen as disorderly, but it also seems to have reinforced the order of society at that time. If someone thought that the upper classes of the mid- to late-

1800s were too spoiled, living indulgent lifestyles, one could refer to the great cost of carrying the progress of civilisation on their shoulders. Neurasthenia was the cross the elite had to bear and, in doing so, they highlighted their eminent value and confirmed the hegemonic order of society. As a mark of honour, neurasthenia demarcated one's elite position and, in an American context, it played into a discourse about the supremacy of American industrial progress. Medically speaking, the diagnosis relied greatly on the concept of nervous energy and, as such, it also played into the contemporary language used for industrial innovations, which could be incorporated in a number of ways.

However, as we saw with Marx, ascribing nervous energy to everyone – not only the elite, but also the workers – generated the potential to disorder the hegemonic structure of society. Freud created space for the psyche within neurasthenia and, in doing so, he made an important distinction between somatic and mental conditions – the latter being a lot less attractive than the old established form of neurasthenia. For the most part, neurasthenia disappeared in the aftermath of the First World War when the number of injured and damaged soldiers was at its highest, which facilitated a range of new diagnoses that aimed to be more specific. On a class or socio-economic level, many of these soldiers had nothing in common, yet they seemed to be suffering from the same group of disorders – specifically, the same mental disorders. In a sense, the diagnosis of neurasthenia disappeared to make way for new categories of disorders with a less 'umbrella-like' character. But it also disappeared because society had fundamentally changed, and thereby the relevance and explanatory potential of neurasthenia became obsolete.

Located Conclusions

Reviewing the history of the conditions of acedia and neurasthenia allows us to approach fatigue as an experience tied to its location. Both acedia and neurasthenia provided a specific explanatory framework for fatigue. To that extent, we see how the condition of neurasthenia and acedia take part in a specific construction of fatigue by locating it within the condition. Thus, the two conditions facilitated the possibility to make fatigue something specific – not only within the condition, but also in more general terms; i.e. fatigue could be said to be caused by – and thus located in – demons, industrial society etc. As the chapter also shows, the specifics of the condition were dependent on a range of factors relating in particular to one's place in society; there were different kinds of acedia

and different kinds of neurasthenia. A worker was said to experience a different kind of acedia and neurasthenia than a monk, or in the latter example, of an American male industrialist; i.e. the definition of fatigue within the description of the condition came to rely on the social class of the person experiencing the condition. This meant that the fatigue within the condition was not an ontological entity applicable to any human being, but was dependent on one's place in society. In essence, a located fatigue within either condition was not only an experience of a condition, but also an experience of one's place in society.

Essentially, the history of neurasthenia and acedia show how a location of fatigue within specific conditions constructs the fatigue as a specific experience that simultaneously plays into pre-existing notions of order and disorder in that society. Rather than argue that acedia and neurasthenia represented radical breaks with the hitherto locations of fatigue, I would argue that they were feasible conditions, and thus feasible locations of fatigue that made sense within the contemporaneous context of society. Naturally, fatigue was located in numerous places and was not restricted to the conditions, but the conditions created the framework in which fatigue could become something specific. While this location and construction of fatigue within the condition would make sense at the time, it also pointed towards a cure that affirmed one's place in society.

This overview has aimed to provide the reader with a sense of how fatigue could be located within different conditions, and how the experience was structured through the locations within the conditions. For the remainder of this thesis, I approach the concept of location via analyses of my empirical fieldwork emphasizing the locations of fatigue within everyday life.

An Ethnological Fieldwork

Ethnologist is that like a biologist?

(Informant at Glostrup hospital)

In the following chapter, I introduce my ethnographical fieldwork approach. In doing so, I discuss my use of ethnological methods in relation to the topic of the thesis, and present some of the most substantial hurdles to doing fieldwork on fatigue among people who have had a stroke.

Project and Fieldwork

The thesis relies deeply on fieldwork conducted during the period from June 2010 to March 2013, almost matching the date of the initiation of the PhD program to its end in September 2013. Prior to the PhD proposal, I had conducted a pilot study at Glostrup Hospital, which included observations at the neurological department among both staff and patients, and participation at a conference on stroke at Glostrup hospital. The ethnological fieldwork conducted for the thesis mainly consists of semi-structured interviews lasting from 30 minutes to 3 hours along with participatory observations. I have done 12 key interviews in the homes of my informants, along with seven days of fieldwork at the outpatient clinic at the neurological department at Glostrup Hospital, where I observed around thirty formalized ten-minute conversations between the nurse and patients. As anthropologist James Spradley emphasizes in *The Ethnographic Interview* (Spradley 1979), ethnographic research happens simultaneously, and thus the findings of this thesis and its emphasis on location have been generated throughout the three years that the thesis came to life.

Upon commencing my fieldwork, I had – through my secondary supervisor – allied myself with nurse Mette Kjærsgaard at Glostrup Hospital, who does consultations with patients who have been hospitalized at the stroke department at Glostrup Hospital in the months after their strokes. This takes place every Thursday at the outpatient clinic and lasts around ten minutes. I was allowed to attend these ten-minute individual consultations, during which the nurse spoke with each patient about his/her experiences upon returning to everyday life, covering a variety of subjects, such as mood changes and sensations of

fatigue. Physical tests were conducted as well, such as measurements of blood pressure and weight. After finishing the interview, the patient would go into the adjacent room, where a doctor would speak with him/her about different issues, particularly concerning use of medicine. Initially, I was allowed to look at the patient journals before consultation with the patient but found little use of them in the interviews. Of the twelve key interviews presented in the thesis, ten have been conducted with former patients at Glostrup Hospital who, at the time of the interview, had had a stroke within the past year. The two other interviews were most kindly facilitated by “Hjernesagen”¹³. In both interviews, the stroke had taken place a number of years prior to the interview.

Locating the Lack

From the very initiation of the thesis, one question was blatantly obvious: On the basis of what criteria would I select my informants? Should I select them based on their sex, age, ethnicity, social status etc., focusing on one particular group, or should I try to find a number of informants who were representative of each of the different classifications? Instead of deciding on a specific parameter to begin with, other than people who had had a stroke and who subsequently reported fatigue, I did some initial research online, particularly focusing on blogs for and by people who had had a stroke or were related to someone who had. In addition, I began my fieldwork and did my first couple of interviews without any classificatory criteria¹⁴. During this process, it dawned on me, after speaking to a couple of informants that fatigue manifested as a *lack* after their stroke; that their new relationship to fatigue was experienced as producing a *lack of something*. What I found was that this lack was tied to experiences of everyday life. It was tied to the things that the fatigue made them incapable of; it was in this sense that the location of fatigue seemed to have become of increased importance in the lives of my informants. They were looking for the cause of their fatigue, and they did so by attempting to find out where their fatigue was located and by doing so to manage their lack. To that extent, my approach to fatigue came to accentuate fatigue as both the presence of something, as well as the lack of something. In effect, my fieldwork itself reflects an attempt to locate fatigue among my informants. It touches upon the question of locating the object of study in order to analyze

¹³ A Danish foundation, translated as ‘The Brain Cause’

¹⁴ Mrs. Henriksen, who will feature often during the thesis, was my first interview and not selected because of her age, sex or ethnicity.

it, and the inherent failure of making the object something specific; i.e. when I initially attempted to define fatigue in order to locate it among my informants, I kept missing the essence of what I eventually argue that fatigue is primarily determined by; namely, a location. To put it differently, I began by looking for something specific; I defined the experience of fatigue in order to go look for it, but found that my definition was in fact reflective of one specific location of numerous and that I was missing all the ways my informants located their fatigue because of my own attempt to locate and define fatigue beforehand. I could not locate fatigue, and eventually it dawned on me, as implied in the introduction, that I wasn't supposed to – rather my informants' locations and what could structure these locations allowed me insight into understanding and continually analyzing their experiences of fatigue. In *The Transformation of Contemporary Health Care* (Moreira 2012) sociologist Tiago Moirera describes how employing the methodological approach – as well as research logic – of *analytical induction* creates a constant loop between the process of data collection and theory formulation (Moreira 2012, 12-13). Although this approach of analytical induction – as will be seen, and as is argued in the introduction – was not intended from the beginning of the thesis, this approach, more or less sums up how the concept of 'location' came into being.

In spite of some initial speculations in deciding *who* I would do my fieldwork amongst, my choice of informants ultimately consisted of people who had had a stroke, who reported fatigue and who agreed that I could contact them. This reflects the very pragmatic take that I adopted in my fieldwork. However, as apparent in the remainder of the thesis, the people who did agree to be contacted were primarily women. Of the twelve main informants with whom I did in-depth interviews, nine were women; yet in all twelve cases, I made the initial contact and arranged the interview with women. This was due to the fact that I planned an interview with the wives of the three male informants. In those interviews, the wives participated as well, and as seen in the analytical chapters, they constitute a large part of the interviews. This leads to questions about: whether more women than men are struck by stroke; whether women are more fatigued than men after stroke; whether women are more affected by changes in their relation to fatigue; whether men are more reluctant to talk about their fatigue etc. I have avoided venturing into such generalizations on gender, and I have also avoided making conclusions based on general

tendencies relating to parameters such as ethnicity and social status. This, in particular, is because I found very little qualitative literature that supports a gender-specific perspective on stroke, or qualitative studies that emphasize the role of ethnicity or social status. This is not to say that there are not a number of qualitative studies that incorporate gender, ethnicity or social status within the research (Eaves 2000); rather, very few of these studies emphasize gender, ethnicity or social status as overtly determinant factors in life after the acute event. Also, in this study, I did not see any indications that gender, ethnicity or social status were particularly important after the acute event, and I can only implore other scholars who may have qualitative material that indicates that gender, ethnicity or social status is of importance to publish on the subject. In brief, I have not emphasized any specific parameters, but allowed the experience of fatigue to be the overriding principle for the choice of informants. Admittedly, before beginning the project, I emphasized recruiting informants over the age of 65, being a part of the Center for Healthy Ageing¹⁵, yet I eventually decided against it. This choice was partly due to practical issues, but also because I found that this parameter excluded informants who were reporting quite immense fatigue after their strokes. In essence, I had the choice of excluding informants who could provide insight into the subject matter on behalf of making an overall argument based on people's age. Instead, I chose to include informants under the age of 65 who reported fatigue and, by including these informants, I have had the opportunity to look at how different times of life may become a part of the location of fatigue; the choice to include these informants thus supported the overall theme that runs throughout the thesis. In that sense, age does figure within the thesis and is often expressed as a location; framing oneself as elderly is a possible location and thus an explanation for fatigue in itself. To that extent, ageing runs as an undercurrent throughout the thesis. Nonetheless, my informants were not chosen because they represent something particular (i.e. a representable diversity), but because they experience (or their spouse experiences that they have) immense fatigue after stroke, and wanted to speak to me about it. It is their concepts of location that I have allowed to structure the second part of the thesis, and it is their

¹⁵ "Center for Healthy Aging is a research center at University of Copenhagen that focuses on interdisciplinary aging research for the advance of better health and reduced frailty". Source <http://healthyaging.ku.dk/>

experiences and problems with living an everyday life with fatigue for which I have allowed space.

Contact

While it had been my strategy to meet the informants at the outpatient clinic, and once there, to arrange an interview with them at another time, doing so proved somewhat awkward – bordering on inappropriate. The reason for this was primarily the character of the consultation, which in its very professional medical setting made my attendance as an ethnologist somewhat out of place. In the instances where I did contact the patients following the consultation with the nurse and tried to explain my project, I often felt that my non-medical background confused the patients and, in a few cases, made them experience a breach of confidence. This could in part be ascribed to my introduction when the interview began being very brief in nature; sometimes the nurse would introduce me to the patient as someone who would sit along, and at other times as an ethnologist, which most of my informants were unfamiliar with, but assumed to be medical as I was participating in a consultation in a medical setting following a formalized medical setup. With the interviews tightly scheduled to last ten minutes, it was not possible nor appropriate to make a longer introduction – I was only an invasive presence in a consultation that was meant to focus on their experiences upon returning to their everyday lives. Instead, along with the nurse, I figured that it would be a better idea if I did not attend the consultations, and that the nurse would give my card to the patients who reported fatigue, asking them if I could call them about an interview. I would then explain in detail what the interview was about and give them a chance to say no – something that I sensed was more difficult for them to say in a medical setting. In the spring of 2011, this became my preferred method in terms of contacting informants, and I owe much to nurse Mette Kjærsgård and my secondary supervisor neuropsychologist Hysse Birgitte Forchammer for allowing me access to the informants, being central gatekeepers, as well as for establishing the initial contact with my informants. In that sense, the outpatient clinic became my gateway to the homes of my eventual informants, providing me with the sense of getting a better understanding of their everyday lives than I would have been able to get in a clinical setting.

An Ethnological Interview

Initially, I had planned to conduct participant observations in the homes of chosen informants for extended periods of time. This choice of method reflected my theoretical standpoint at the time, which was highly influenced by existentialist philosophy. Inspired by the descriptions of fatigue in *Existence and Existents* by Lévinas (Levinas 2001 [1947]), I wished to be present at the particular time when the immense sensation of fatigue, as I imagined it, occurred. In essence, I wanted to witness the struggle with fatigue, highlighting one's contract with being, which Lévinas so eloquently pinpoints in his work. As it happened, most of my informants expressed little interest in me watching them extremely fatigued on the verge of falling asleep, it being a very intimate situation. Had I pushed for it, it might have been possible with some of the informants, but I soon came to realize that it would not contribute much to the analysis. Instead, I chose to resort to an even more traditional method of fieldwork within ethnology; namely, the interview (Kaijser and Öhlander 2001). The importance of the interview within ethnological fieldwork is difficult to overemphasize, as it provides the ethnologist with multifaceted perspectives on a subject matter (Kaijser and Öhlander 2001, 55), and historically it reaches back to the early folkstudies that would later come to establish ethnology as a science. As frustrating as it may be to have interview material that seems to point in many directions, it does however reflect experienced life and practice. From my own experience, there are few things as unproductive as interviews that say exactly what you thought they would say. Rather, unexpected twists and an odd story, are sometimes what reminds the ethnologist that (s)he is interviewing a human being and not a generative ideal type (Weber 1949 [1903-1917]).

The interviews I conducted painted a very vivid picture of how the stroke had entered each informant's everyday life, and how it had become altered by it – with a specific emphasis on fatigue. Furthermore, during the interviews, it occurred to me that there was a certain mismatch in my initial approach to my fieldwork that emphasized participant observation at the moments when fatigue enveloped my informants, as this would have removed the word 'participant' from participant observation and make my informants more similar to objects of study than people experiencing, relating to and reflecting on their fatigue. Anthropologist Martin Gerard Forsey suggests that engaged listening is at least as significant as participant observation and points to ethnography as being more

aural than ocular; he argues that the word ‘observation’ ought to be replaced by ‘listening’ in participant observation (Gerard Forsey 2010, 561). Seeing it from an existentialist point of view, it also became apparent that, while fatigue is something that makes one aware of one’s existence, it is also a condition in which one is caught. In that respect, fatigue is a limitation on lived life but barely communicable as such when one feels fatigued. As ethnologists Orvar Löfgren and Billy Ehn note, the ever-more prevalent question within Ethnology is how to study emotions and sense impressions as phenomena that cannot be captured in words or images (Ehn and Löfgren 2005, 15). In many of my interviews, I would thus notice my informants getting tired, but in the process, it seemed that fatigue turned from being a matter of which they could speak to becoming the experience that left them out of communicable reach. Furthermore, my idea of doing participatory observation seemed even more absurd, as being social necessitates that one step up to one’s being¹⁶ – something which Lévinas points out is notoriously difficult when fatigued (Levinas 2001 [1947]). In essence, my own determination to be socially interactive through participant observation negated the experience that I wanted to research. One situation in particular made me aware of this mismatch. I had participated in a number of consultations one Thursday at the beginning of 2011 and had not contacted any of the patients after the consultation, as most of them were not reporting any experiences of fatigue. However, one patient had caught my attention, as she reported quite extreme fatigue along with experiences of pain. She seemed slightly agitated, so I did not explain my project to her right away but was allowed to get her phone number. When I got on the bus home from Glostrup Hospital, I saw that the patient was going on the same bus. To avoid an awkward situation with a possible informant, I decided to contact her – explaining my project to her on the bus. While she was very accommodating, she nonetheless told me how her fatigue at the time made it difficult for her to talk any further, and explained that the consultation had taken its toll on her, making her very tired and just wanting to get home. This very instance made obvious the necessary distance between the experience of fatigue and reflecting on one’s fatigue as an object. This also made me aware that it would likely be easier for my informants to speak about their fatigue in those settings where they could control or manage their experience of fatigue and thus reflect on

¹⁶ Lévinas argues that fatigue makes one aware of how one has a contract with one’s being; a contract that has to be met but which it is impossible to meet in the state of fatigue. This is further explored in “A Disrupted Return to Everyday Life”.

it. I gathered that a more habitual environment where their everyday lives unfolded would prove more appropriate and, in many cases, this assumption proved quite correct. A natural advantage of this was also that meeting my informants in the environment in which they spent a large amount of time gave me a very tangible impression of their everyday lives.

As the interviews gradually progressed, I discovered that there was very little need for interference on my part. The informants were very interested in telling their stories, and in many cases also in venting their frustrations. Due to this, listening became a large part of the interviews, which gradually became less and less structured, as I discovered both the potential I had of reciprocity by listening, and the way in which the transcripts highlighted issues I had not imagined would be of any importance, nor would ever think about. In many cases, however, listening also meant what is implied in the word to avoid filling the silences. This proved a most valuable tool, which prompted my informants to connect and reflect on otherwise seemingly unrelated issues.

In no instance did I feel that I needed to interrupt during the interviews; this was partly due to the interview guide, which I revised a couple of times, but which kept me on track throughout the interview. However, the length of the interviews varied greatly; in the most extreme cases they lasted for as long as three hours and as short as half an hour. The interview that lasted half an hour was deliberately shortened due to the presence of a carpenter who had to drill underneath the kitchen sink to put an end to an invasion of mice, which had been upsetting the sleep pattern of the informant.

I have taped and transcribed all the key interviews. Although I had the opportunity to have my interviews transcribed by a student assistant, I chose to do the transcription myself, due to the fact that it imposes a rather intense review of the interview, thus giving me the chance to review my questions, begin the process of coding and analysing as well as assess the quality of the interview. Unlike previous experiences with recording interviews¹⁷, the informants did not hesitate to agree when I asked if I could record the interviews. In one interview, I was even asked where my tape recorder was before the interview began

¹⁷ The fieldwork for my Master's thesis was conducted among traumatized American veterans, none of whom were very keen to be recorded.

and I had told my informant about the possibility of recording the interview. This was not because the informant had previously been interviewed by a social scientist and thus had experienced the setup, but, as she explained to me, because the word “interview” in her understanding implied recording.

The (Medical) Professional – Ethics

As mentioned in the beginning of this chapter, I was initially allowed to review the patient journals, and did so the first couple of times I went to the outpatient clinic. Besides experiencing this act as an acknowledgment of my studies – feeling that I had gained an access that I had never experienced before – it also created a power asymmetry. At the outpatient clinic, I would look through the patient journals with the nurse before the patients came in, and I would note what she believed would be important to speak about in the conversation with the patient. As the nurse spoke with the patient, I would begin to notice how the patient journal came into play during the conversation, and gradually I could see in the patient journals what would be addressed without the help of the nurse. While this did feel empowering before meeting the patient, it also made my experience of meeting the patient feel unequal. The nurse was extremely professional in handling this discrepancy, but I could not help but feel that because I knew something about the patients before even meeting them that I could potentially catch them telling a lie (although I would never do so). In any interview situation there is, as Eva Fägerborg notes, almost always a discrepancy of power between the informant and the ethnologist (Kaijser and Öhlander 2001, 66), but what I experienced during the patients’ conversations with the nurse was that I had knowledge about the patients, and that this knowledge entailed a responsibility to be able to answer the patient if they asked me any medical questions. During a conversation between the nurse and a patient and her husband, the nurse left the room to find a doctor who she could ask about a question the couple had. Being seated alone with the couple in a medical setting, I attempted to divert any questions by talking about the weather. Nonetheless, the couple knew that I had the patient journal, and I expected that they would ask me a medical question at any moment while the nurse was away. Luckily, the nurse returned before we had finished talking about the different shades of grey that characterize late autumn in Denmark, but that situation in particular made me aware of the obligation that came with receiving the patient journals – to be able to

reciprocate by acting as a medical authority. From then on, I continued to receive the medical journals for a little while, although I stopped reading them, and it was finally decided that I would no longer receive them. The patient journals added to the contemplations I had had from the very start of my fieldwork – of not being confused for a medical professional – and simultaneously gave me a minor insight into the relation between medical professional and patient.

In terms of ensuring that I would not be mistaken for a medical professional, visiting my informants in an environment that they were accustomed to seemed to be a good idea, as any eventual disappointment with my lack of medical abilities would possibly be countered by me visiting them and not the other way around – getting out of the house was often framed as a task in itself. Furthermore, avoiding an institutionalized setting seemed to allow me not to confuse my informants in terms of my intentions. I nonetheless did experience a couple of times where I was asked whether or not I was a doctor. Sometimes, although I did my best to explain my profession and my intentions before beginning the actual interview, I would be addressed as a medical professional or as a psychologist. In an interview with 85-year-old Mrs. Johnsen, she initiated the conversation by asking me about a questionnaire that she had received from a hospital concerning her health. In the questionnaire, there was a question about her own view on her health. She had five possible answers, ranging from really well to really bad, and Mrs. Johnsen was in doubt as what to answer as she had been treated for polio when she was 18, and had had to deal with the repercussions ever since. She had learnt to live with it, walking with a cane most of her life. After an accident a year prior to her stroke, she had been forced to use a wheelchair, but Mrs. Johnsen had no idea as what to answer as, considering the circumstances and her age, she felt in relatively good health. Being in doubt nonetheless, she asked me what she was supposed to answer, whereupon I tried to divert the question, not knowing what to tell her. When I had done so, she asked me if I was not a doctor, who understood the logic of the questions in the questionnaire, so as to be able to translate her experience into what she thought was required by the questionnaire. She had consulted a physiotherapist at the training center she attended, and had shown the physiotherapist my card. The physiotherapist had been convinced that I was a doctor even though I had made it clear to Mrs. Johnsen on the phone when arranging the interview that I did not

have any medical training. Eventually, I tried to explain to her how questionnaires differ from the kind of interview that we were about to initiate, as the interview would leave her with more than five possible answers, to answer a question that she found very complex – but hopefully, allowing her to express how she experienced her condition.

That I had a certain expertise in strokes placed me in situations where I was asked for answers about whether my informants' experiences were normal or not. The interview with Mrs. Johnsen provides a good example of this:

(Mrs. Johnsen) I have problems using my arms, but I don't know if it's that (the stroke) or polio. Am I not somewhat atypical?

(MA) *I don't know, many people experience that they are atypical...*

(Mrs. Johnsen) Well, yes but the thing with me huffing and puffing like that makes me think whether it's my lungs, but then again I have been examined at the hospital, and there's nothing there.

Mrs. Johnsen is clearly confused in terms of locating her overall state of health, and it becomes a recurring theme throughout the interview, with her trying to connect the dots and asking me for help once in a while. Similarly Mrs. Herschel, being very disillusioned by her current situation, prompts me to reassure her that a lot of people feel like she is feeling, after which she asks me whether things are going to get any better for her:

(Mrs. Herschel) I think it's the frustration with me, being really afraid that it's never going to be any different. I think I have a hard time focusing, also in relation to my work. I can't remember what I was capable of remembering before.

(MA) *No, a lot of people deal with that...*

(Mrs. Herschel) Okay, does it come back to you?

(MA) *For some it does...*

(Mrs. Herschel) You have to say yes now.

(MA) *Many of the people I've spoken to experience it coming back.*

Most of the time, when confronted with questions such as the ones posed by Mrs. Herschel and Mrs. Johnsen, I did not know what to answer and instead I would either divert the question or try to explain my profession. In the majority of instances, me being unable to

reciprocate made my informants seem slightly dissatisfied. The above quote from the interview with Mrs. Herschel, shows how she is in need of reassurance that things are going to get better, and I try to reassure as best I can, without providing her with false hope. By the end of the interview, Mrs. Herschel expressed gratitude at having had the possibility to share her experiences with a person who was only interested in listening. This comment made it increasingly poignant that listening is not only a passive exercise, but aside from body language etc., also entails saying the right things at the right time – showing that one has understood what is being said, and able to empathize by providing the reassurance needed in a certain situation.

As the attentive reader may have noticed, everyday life is a concept often mentioned in the thesis. Thus, it is in the everyday lives of the informants that I attempt to approach the experiences of fatigue after stroke. Everyday life, besides being a traditional ethnological field of study, also represents a certain entity that it is difficult to define. Nonetheless, we often tend to make use of the concept as if it is self-explanatory. In the analytical chapters to follow, I therefore begin by exploring the concept of everyday life and presenting a specific approach to everyday life, which I make use of in my analyses of the informants' experiences of fatigue in everyday life.

A Disrupted Return to Everyday Life

The Concept of Everyday Life

Within the field of Ethnology, there are numerous studies that take their point of departure in everyday life. Many philosophers and social scientists have also addressed the concept: Jean Baudrillard (Baudrillard 2005 [1968]), Walter Benjamin (Benjamin 2002 [1983]), Sigmund Freud (Freud 2003 [1901]), Henri Lefebvre (Lefebvre 2002 [1947], 2000 [1971]), Michel de Certeau (de Certeau 2011 [1980]), to mention a few, all reflect upon the concept of everyday life. In general, one could argue that research into everyday life can be divided as such: studies that focus on everyday life as a way to examine larger themes in society (a classic theme for many Marxist studies (Lukacs 2005 [1970])); and those that focus on day-to-day practices like washing, cooking, etc.

Being such a broad and well-explored concept, it is beyond the framework of this thesis to provide an all-encompassing overview. Rather, I propose to look at everyday life through approaching social scientist Ben Highmore's recent collection of essays by philosophers and social scientists on the subject of everyday life, in which Highmore attempts to synthesize the essays to trace the developments of everyday life. This leads Highmore to emphasize the idea of everyday life as consisting of routines and practices, and thus a focus on the actuality of everyday life in its familiarity – something that Billy Ehn and Orvar Löfgren also emphasize in *The Secret World of Doing Nothing* (Ehn and Löfgren 2010, 79). As Highmore points out, everyday life is seldom the problematic but rather the scene wherein a problematic is unfolded (Highmore 2002a, viii). To a certain extent, everyday life represents a repetition of actions and thus it presents us with a specific world that we constantly encounter. As such, it is quantifiable – yet, to another extent, it has a qualitative value that could be considered “everydayness” (Highmore 2002a, 1). With modern life, many things disrupt everyday life and, being unfamiliar, the need to constantly manage these things marks the failures as well as successes of everyday life. These things are managed through either incorporation or repulsion, which are both processes of time, and time is intrinsic to the concept of everyday life due to it being experienced both through and in time.

According to Highmore, new experiences of temporality in Western modernity are tied to the institutionalization of work and also the standardization of time. As ethnologists Jonas Frykman and Orvar Löfgren point out in *Det Kultiverte Mennesket*, the introduction of mechanical clocks at the workplace established a linearity of time and working patterns that related time to money (Frykman and Löfgren 1994, 24). However, as Highmore argues, this change had already begun in the fourteenth century and was not the sole reason for change in what we now know as “modern time”. Instead, according to Highmore, the representation and experience of time became radically altered with the establishment of institutions in society, such as churches, schools, hospitals, etc. However, time was still very much an object of local negotiations, and the affair of travelling was somewhat unsynchronized (Highmore 2002b, 5). With more expedient means of transportation – such as railways – time became increasingly globalized; this necessitated that time became standardized, which “reconfigured the tempo of the everyday” (Highmore 2002b, 6). Modern time became a time of synchronized minutes and seconds, and the importance of limiting time loss was reflected in a range of re-organizations at the workplace as well as the “discovery” of pathological conditions such as neurasthenia. Although one might think that the measurement of time would break the monotony of everyday life – every second and every minute being different from the other – the story of the measurement of time follows the story of monotony. We can imagine a worker on the assembly line, clocking in and out at and having lunch at a certain time each day, which makes every day seem the same. The worker’s monotonous labour on the assembly line constitutes the time between these points.

Literary critic and anthropologist Susan Stewart argues that it was the daily repetition of counting that reduced differences to similarities (Stewart 1984, 14). In *The Politics of Life Itself* (2006), sociologist Nikolas Rose adds that the conditions and types of work were radically altered throughout the 19th century. This caused work to become increasingly tied to the notion of “lost time”, coupled with an array of different remedies to counter such a “waste”; these ranged from social reforms to industrial psychology (Rose 2006, 59). Industrial psychology in particular was a forceful remedy, which promoted matching instincts with types of work in order to secure a more stable workforce. As instincts were

considered to be universal in nature but particularistic in degree, the workers' physical instability and mental disorders emerged from not carefully constructing an order within the factory that accounted for the subjectivity of the worker. In this way, industrial inefficiency was tied to the subjectivity of the worker; a subjectivity that also had a life outside the confines of the factory. This relation between individual subjectivity and work pointed to everyday life as one of the pillars by which maximum efficiency could be ensured. This included an increasing interest in understanding the worker as something more than his physical capabilities and, at this point, both the human psyche as well as social dimensions became more important (Rabinbach 1992, 256; Rose 2006, 69). Not surprisingly, the up-and-coming social sciences began to map the social dimensions of the worker(s), including everyday life – but how was one to approach something as multidimensional as everyday life? Highmore suggests that some social scientists were compelled to implement an already tested approach: they would look at the assumed opposites of everyday life integrated within itself; in other words, the uncanny. In effect, everyday life became all the uncanny things believed to support such a life. Freud looked for repressed desires; Marx looked for expressions of alienation, etc. Highmore's collection includes a range of essays by authors who share the common feature that they are looking for that which makes an essentially ordinary everyday life extraordinary – or, at least, to be an expression of something else. An ethnologist might notice how there is no division between everyday life as related to work and everyday life as related to leisure time. This is because, for Highmore, everyday life contains no such division; rather, it is configured through its actuality of familiarity. As Highmore so eloquently puts it, everyday life is “the landscape closest to us, the world most immediately met” (Highmore 2002a, 1); as such, everyday life – whether at work or at home – is the life lived in this landscape.

From this collection of essays, one thing is certain: the definition of “everyday life” is not clear-cut. This becomes particularly obvious if we look – as I do in the following part of the thesis – at the concept of everyday life in terms of the word “return”. Returning seems to imply that one can return to something that somehow has the same static essence – for example, when we leave home in the morning and, upon our return, find that nothing has changed (hopefully) and, although we have been away for eight or nine hours, the place still feels the same. Returning also implies that everyday life is comprised of everyday

activities to which one can return – they have a certain quality that retains their “aura” of being everyday activities, but without any clear rule to define what is an activity of everyday life and what is not.

This is the problem with the concept of everyday life: although it might signify something that appears to be static, everyday activities highlight how this life is simultaneously and constantly on the move. In order to delve deeper into what seems to be the unifying factor in relation to everyday life – i.e., the actuality of familiarity– I draw upon the existentialism of Heidegger, a philosopher who, as Jacques Derrida confirmed in “La différance” (Derrida 2005 [1972]), is the father of asking questions that restructure the inner core of metaphysics, and thus the concepts and – allow me to say it – the familiarity of everyday life that we take for granted.

An Existentialist Phenomenological Approach to Everyday Life

In his seminal work *Sein und Zeit* (Heidegger 1962 [1927]-b), Heidegger introduced an approach to *being* that ultimately revolutionized existentialist thinking in Western philosophy. Heidegger’s confrontation with metaphysics is probably the most well-known feature of *Sein und Zeit*. Here, Heidegger attempts to restructure metaphysics by questioning the prevailing paradigms that regular philosophical systems typically present. Most importantly, Heidegger poses two questions: “What do we mean when we use the expression ‘Being’?” and “What is the meaning of being in itself?” The first question is a semantic challenge to the sciences, while the second question challenges the pre-understanding of the meaning of being in practical-moral life (Safranski 1999, 149). Heidegger’s point is that the question about the meaning of being has been asked in the wrong way – and, actually, in such a wrong way that the meaning of the question itself is no longer understood, even though it is continually posed within the natural sciences and in the practical-moral life (ibid.). The sciences fail by objectifying the human being in the same way as objects in the world yet, as Heidegger frames it, being is a movement in time that does not end as long as something *is* being. This is what differentiates the human being from the object: that the human being is in a continual being – a so-called *Dasein*. Furthermore, a human being has a relation to his own being, and this is what we call existence. The relation that *Dasein* has to existence is the reason why the human being is

partly “thrown into” Dasein while simultaneously being in being. As Jean-Paul Sartre notes, “we have a relation to ourselves and our own being, and we have to make something of what we are made into” (Sartre 2012 [1943]). Dasein and existence are thus recognizable in German philosopher Rudiger Safranski’s statement:

Dasein or existence therefore means we not only exist, but we perceive also that we exist. And we are never finished like something that exists, we cannot walk around ourselves; at each point we are open for a future. We must *lead* our lives. We are charged with ourselves. We are, what we become. (Safranski 1999, 150)

Returning to the concept of everyday life, we might now ask: what is the relationship between Dasein and everyday life? Heidegger offers us an answer when he claims that we are entrenched in everyday life – and, actually, we are so entrenched that things often appear as if they do not appear at all. He makes this obvious by using the terms *vorhandensein* and *zuhandensein* to emphasize that we are acutely aware of some things (*vorhandensein*), whereas others disappear in the midst of things (*zuhandensein*). For example, when I sit on my chair at the office, I may not notice its soft features – they are *zuhandensein*. But after my colleague spills a glass of water on my chair, I suddenly notice that its usual soft features are now soaking wet and uncomfortable – and the chair becomes *vorhandensein*. In brief, the chair and its features suddenly appear. When something suddenly becomes *vorhandensein* in this way, it often happens as a manner of resistance, pulling us out of our relation to *zuhandensein*. In *A Philosophy of Boredom* (2005), Norwegian philosopher Lars Svendsen argues that something like boredom grows out of one’s everyday relation to things – i.e., through a relation to things in which the world itself appears as *zuhandensein*. To that extent, boredom is a loss of one’s relation to the world (Svendsen 2005), and the temporality of everyday life may become less of a horizon of possibility and more of something to let pass. This inauthentic kind of life, as Heidegger non-judgmentally puts it, is the thief of time, as this movement towards the world has no time. In other words, the temporality of everyday life conjures an indifference to the world it reveals. It is in everyday life that we become more and more like the figure of *Das Man* (the Man); a figure whose substitutability denies Dasein access to the fundamentality of being – namely, death (Langan 1959, 56). To Heidegger, this is essentially the problem of everyday life – that we do not live mindful of the finitude that ultimately characterizes our being. This however, does not mean that the experience of death is within the scope of

mortal experience. Death is a certainty, of which we cannot say or know anything about except its eventual occurrence. Thus, the ontologies offered by religious authorities claim to have access to experiences that go beyond finitude, but this insight is, according to Heidegger, ultimately beyond the reachable experiences of the mortal being and thus we trick ourselves if we believe that death is liminal, as suggested by these ontologies. We cannot experience death, although our being is a Being-towards-death. As Heidegger so despondently frames it:

Factically, there are many who, proximally and for the most part, do not know about death; but this must not be passed off as a ground for proving that Being-towards-death does not belong to Dasein 'universally'. It only proves that proximally and for the most part Dasein covers up its ownmost Being-towards death, fleeing in the face of it. Factically, Dasein is dying as long as it exists...(Heidegger 1962 [1927]-a, 295)

The attention to one's own finitude, and thus one's essential thrownness into existence, may come from Angst/Anxiety, wherein we become aware of the finality of being and thus also the nothingness that simultaneously constitutes our freedom, facilitating a more direct approach and care (*Sorge*) about life (*ibid.*). But whereas, for Heidegger, Angst becomes the crucial feature that enlightens one about the finitude of Dasein – for Emmanuel Lévinas, this feature is more closely associated with the sensation of fatigue. According to Lévinas, fatigue highlights the essential burden of being, and it reveals the contract between the being and the Being; this then creates an awareness of how one must “catch up to” one's own being, while it may also point to the impossibility of escape from one's being (Levinas 2001 [1947]). With reference to Heidegger, we are not only being but we are in a relation to this being. This becomes acutely obvious in those instances where our being presents itself as opposed to us – as something that has to be assumed as an unavoidable part of being. This ultimately results in the recognition that one lags behind one's existence and has to assume it. Both Lévinas and Heidegger thus approach two different – albeit somewhat similar – concepts of being. Angst makes us aware of our being by referring to its finitude, while fatigue makes us aware of our contract with being as we are in being. In essence, these are both revolutionary insights that, as Heidegger explains, may provide one with a radical freedom – setting one free from the dogmas of ontologies – but which also insist on one's finitude. Reframed this way, we might say that everyday life

is the life in which one has no awareness of one's own being-in-the-world. Everyday life is the thief of time and the thief of one's relation to death.

Returning to the concept of time, everyday life is thus characterized by a following of "points of now"/*jetz-punkte*, in which time is presented as indefinite. According to French philosopher Henri Bergson's theories discussing Zeno's arrow paradox¹⁸, time is made up of indefinite and immobile points constituting infinity, but a human's life can never be infinite and immobile (Bergson 2007 [1911]). Instead, as Heidegger claims, one is born dying, and this fact should make us aware of our finitude, and thus the individual movement towards death itself rather than the normative points we are thought to occupy in life (Langan 1959, 57). To summarize: Heidegger makes it clear that everyday life is constituted by forgetting one's existence, as remembering this existence points towards death. It also means having a relation to things in which they do not appear as *vorhandensein*, and it means avoiding the anxiety that makes one's relation to existence so blatantly obvious. In that sense, living an everyday life is also an ability that, as I show, is challenged by the event of the stroke.

In contrast to phenomenologist and philosopher Drew Leder (Leder 1990), who is a well-known figure within social studies of health and illness focusing on the experience of the body as *dys-appearing* when encountering pain or other bodily discomfort that may lead to an alienation towards one's body, I – aided by Heidegger – explore the idea that man lives among things, and it is this relation that constitutes man. Thus, it is not only the body that meets resistance but also the entire world of being, which may meet resistance when confronted with the experience of disruption; this disruption often prompts a new relation to things that were formerly *zuhandensein*. This highlights the important distinction between Leder's phenomenological approach – heavily inspired by French phenomenologist Maurice Merleau-Ponty – that emphasizes the lived body as what constitutes the world-as-experienced, and the Heideggerian existentialist-phenomenological approach in which being-in-the-world is more primary than bodily being (Askay 1999). One might argue that Leder takes Merleau-Ponty too far in arguing

¹⁸ Zeno of Elea (490 BC – 430 BC) was a pre-Socratic Greek philosopher, whose most famous text (Elea and Lee 1936) concerns motion as later described by Aristotle (384 BC – 322 BC) in "Physics" (Aristotle 1999 [350 BCE]).

that the lived body is primary to existence, whereas Merleau-Ponty rather framed them as being equiprimordial (Merleau-Ponty 2005 [1945], 192). However, Merleau-Ponty's approach is closer to Heidegger, in that Heidegger argues that being-in-the-world implies more than bodily being; e.g. an openness towards the world, while also acknowledging how bodily being is co-determinant of Dasein's existence as being-in-the-world (Askay 1999, 32).

A Disrupted Return to Everyday Life

As presented in the introduction, it is a common assumption that a stroke disrupts one's life; both popular literature and popular media are factors that strongly contribute to painting such a picture of the after-effects of a stroke. Some of the most well-known social-scientific articles and books on stroke are *Disrupted Lives* by Becker (Becker 1997), *Illness, Biography, and the Interpretation of Self Following a Stroke* by Kaufman (Kaufman 1988a) and *Chronic Illness as Biographical Disruption* by Bury (Bury 1982). In all of these, the stroke is featured as a disruption to life that impacts the narrative identity of the people who have suffered a stroke and thus also impacts their attempts to create meaning out of the narratives. In essence, Bury, Kaufman and Becker all argue that the advent of a stroke disrupts meaning, and that it is usually somewhat of a struggle for people to create a new narrative to support their changed identities. In terms of always involving a disruption of narratives, this perception of stroke is nonetheless challenged in the article "Illness in the Context of Older Age: the Case of Stroke" by Pound, Gompertz and Ebrahim (Pound, Gompertz, and Ebrahim 1998a), wherein the authors argue that the image of stroke as a biographical disruption is somewhat one-sided. Referring to, amongst others, Pierret and Carricaburu's article (Carricaburu and Pierret 1995) about HIV infection among gay men with hemophilia – in which they pose the argument that the infection is not so much a disruption of a biography as it is a reinforcement of the biography – Pound, Gompert and Ebrahim suggest that the experience of previous illnesses may sometimes ensure that a stroke may not be experienced as a disruption, but rather as part of one's overall illness narrative. In their view, age is a particularly important aspect in that regard, as they assume that a person has experienced more illnesses while getting older. Also, a stroke may be a crisis among crises, and thus not a singular event that in itself alters one's conditions; rather, it participates in a melee of incidents. To that extent, a stroke might not be

abnormal, but instead something that is intrinsically tied to an experience of normalcy – perhaps even reinforcing a biographical experience¹⁹.

Whereas Pound, Gompert and Ebrahim put much-needed emphasis on the multifaceted experience of having a stroke, they are nonetheless somewhat ageist in their assumptions about how elderly people have had more experience with illness, and that they are therefore better at coping with the experience of having a stroke. However, their point that a stroke is often portrayed as something that one experiences as a disruption – and that this was not always the case – was interesting to me as I initiated my fieldwork. During my time at the hospital in Glostrup, as I listened to conversations in the outpatient clinic, I did often hear patients telling the nurses that they felt that the stroke had not been too bad, and that they were getting on with their lives without thinking about their strokes very much. In some cases, the patients had had several strokes, and it was hard for them to differentiate between which stroke, in their opinion, had dramatically changed their lives; in some cases, the stroke had been, as Pound, Gompert and Ebrahim point out, “just” another illness in a line of multiple afflictions. Nonetheless this chapter focuses on those people who experienced a stroke as disruptive and who are experiencing a change in their sensation of fatigue since their strokes. The informants featured in this chapter have all had a stroke within the last few years and, while some of them are dealing with a degree of paralysis in different parts of their bodies, none of my informants are struggling with severe aphasia or more extreme debilitating sensations of numbness; still others are completely unaffected by such a lack of sensation. Instead, they all accentuate the experience of fatigue as the most debilitating sensation to result from their strokes.

In the following, I present how my informants deal with the disruptive effects of the stroke in everyday life. I do so by looking at how the strokes are disruptive from the existentialist-phenomenological approach outlined earlier. It is my contention that the stroke *dis*-locates previous experiences of fatigue in everyday life, making former locations less accountable, as well as creating new locations of fatigue. I thus approach how the stroke poses new existential questions, and how these questions may be essential in restructuring the locations of fatigue.

¹⁹ I return to this issue in the chapter “The Narratives of Fatigue”.

In the fieldwork I conducted at the outpatient clinic of Glostrup Hospital, many of my informants asked the nurses about the likelihood that they would have another stroke – most of them expected that, since it had happened once, it was liable to happen again. But because most of the informants were taking blood-pressure medication (which lowers the risk of reoccurrence), the nurses were able to tell them that this was not the case. However, for my informants, not knowing whether a stroke would strike again is a fact of everyday life – a fact for which most of them seek reassurance. In an illustrative example, Ms. Petersen talks about her treatment at the hospital and then returning to her home:

(Ms. Petersen)...I was hospitalized around 3:30 in the afternoon, but I only came to the ward at around midnight. It started with a doctor who came and looked and then you were thrown out 24 hours after you had been hospitalized, and then you are just left to yourself on the street. I could hardly get down the stairs and underneath the road and stuff [there is a highway close to Glostrup hospital, where one has to go underneath the road], and then go back with the bus. You just stand there completely powerless and then you get home, and suddenly you are all alone, and then it suddenly hits you that you've had a stroke. Then you get scared of being there and then I call...the day after I had a minor stroke again and I called Glostrup but they told me to call my doctor. So you could say that it has become a completely different world one has started to live in.

Later in the interview, she explicates her anxiety about spending the first couple of days at home alone:

(Ms. Petersen) I was really scared. I was scarringly scared and I did not dare to lie down. Those seizures I got just from turning my face to the wall....I would lay on my left side and then it came, and I simply did not dare to do that. A long time went by before I dared turn around on this side I was uncomfortable with being here, because what would happen now, and there's no one here, and if I lay here and can't reach the telephone, so I was in a state of panic. The first night I think I slept for half an hour, and that was on top of my duvet and not underneath it while wearing all my clothes I didn't dare to rest because I was scared what would happen, and it also came back Wednesday morning. I thought, "no, what's going on with me". So I actually did not sleep very much those nights up until Friday where I went to my doctor who immediately sent me to Kildegården [a nurse-staffed senior center for acute hospitalization].

Upon returning from Kildegården she continued to experience this anxiety:

(Ms. Petersen) In the beginning I had both lights on my table turned on, and the television...the sound... It was like I had to make my brain focus on those sounds, because when there was complete quietness, I just couldn't sleep.

As we can see from the excerpt, Ms. Petersen does not wish to return to her everyday life after just having had a stroke; rather, she wants to stay close to people who can monitor her. Thus, her anxiety about not knowing whether the stroke will strike again is not only manifested in her inability to rest and have a “normal everyday life”, but also in her entire existence. In other words, her life has changed because of the stroke, and returning to an everyday life does not provide her with any comfort; rather, the effort she makes to secure her new position in life becomes accentuated as important. One could also argue that Ms. Petersen’s inability to return to everyday life is caused by her inability to grasp how to return to everyday life cf. the point about the paradox of returning to everyday life as if it is a stable entity.

The existentialism apparent in Ms. Petersen’s use of the concept of Angst calls attention to one of the central features of existentialism, which provides an entry of analysis into what Angst makes us aware of. Heidegger’s analysis of the human relationship to death reveals how our notion of time is corrupted by an intrinsic tendency to escape from the *disturbing timeliness of existence*. As Heidegger claims, we seek a specific point in time to which to tie our existence. The way in which one asks oneself about the meaning of being – i.e., as if it was already there – is essentially a feature of being escaping from its own timeliness. Thus, Heidegger would say that questions asked metaphysically can only be answered metaphysically. Heidegger, paraphrasing Søren Kierkegaard in *Sickness until Death* (Kierkegaard 2011 [1849]), sees a similarity between the states of despair and Angst: they are both a state of being in which one’s being appears to be separated from being – thus facilitating the question about one’s being in time. Being in Angst makes the question about the meaning of being apparent as a question in and of itself, unrelated to anything in particular. As opposed to fear, Angst is not directed towards something specific, but is rather the indefinite and limitless that may pull one out of his intimate and established relationship with the world – a world of established truths and notions of a God (Safranski 1998, 170). In this way, Angst pulls one’s being as though it was a document going through a shredder, but the most valuable information – which was formerly concealed by the other pieces – remains on the document; namely, that being is free to choose and “catch itself”. Thus, Angst is a phenomenon of distance: by opening the free horizon of being for us, it moves us from being stuck in our being-in-the-world. According to

Heidegger, it is exactly this freedom that Angst brings to us that it is difficult to control. And, as it manifests our relationship to death, this Angst creates endless possibilities of being. In a similar vein, Kierkegaard argues that the radical freedom with which one is presented can only be overcome by jumping into faith – which is exactly what Heidegger repudiates. If we search for the meaning of being, we do not find any other answer than time, and the relationship between meaning and time is, as Rudiger Safranski eloquently puts it:

The meaning is Time, but Time “gives” no meaning (Safranski 1999, 153)

In essence, while simultaneously killing us, time provides us with a certain freedom. For the same reason, it is essential that we include time in our being-in-the-world to which we have a distanced relationship, outside of the state of Angst. In effect, Angst absolves everyday life from the confines of an endless time, but in doing so it presents one with the abyss of freedom – also being the abyss of death. It is a state of acute awareness of one's being.

When Ms. Petersen goes to bed with her clothes on, the cell phone next to her and the television turned on to create the illusion of a presence, she does not “go to sleep” in a way that allows for sleep. She lays in her bed, waiting for sleep to summon her; she knows that she might have to surrender to it, but sleep is not really welcome. In writing about the summoning of sleep in *Phenomenology of Perception* (2005), Merleau-Ponty describes it as such:

Sleep comes when a certain voluntary attitude suddenly receives from outside the confirmation for which it was waiting. I am breathing deeply and slowly in order to summon sleep, and suddenly it is as if my mouth were connected to some great lung outside myself which alternately calls forth and forces back my breath. A certain rhythm of respiration, which a moment ago I voluntarily maintained, now becomes my very being, and sleep, until now aimed at as a significance, suddenly becomes a situation. (Merleau-Ponty 2005 [1945], 245-246)

Merleau-Ponty's idea about a certain voluntary attitude is somewhat ambiguous, but a certain dismantling is part of an acceptance of, or even a call for, the summoning of sleep. Most of us know this dismantling as a routine of everyday life. We brush our teeth, undress and/or put on our pajamas, climb into bed and turn off the lights. In the darkness, we try to turn off our senses and prepare ourselves for the arrival of sleep. We accept sleep and have summoned it through our daily routines or rituals. But Ms. Petersen does no such

thing. Her relationship to sleep is altered because of the existentialist Angst that resulted from the event of her stroke. There is a routine in what she does, but it is what we might call a “routine of opposites”: she lies on top of the duvet, clutching her phone with the television turned on. We can imagine a similar scenario when a person is afraid of a burglar entering the house. Ms. Petersen’s television is on, alluding to an extra presence for the being entering the house to hear, the phone is in her hand to summon help and her clothes are on in case she needs to flee the house. In her state of Angst, sleep is a necessary evil that cannot be trusted. Thus, she does not actively summon sleep, but is aware of its necessity, and she begrudgingly accepts this. She also explains how she felt very fatigued after her stroke, and how she could only allow sleep to summon her after she was admitted to Kildegården. The fact that she was able to fall asleep there adds a social dimension to the existentialist analysis: Ms. Petersen lives alone and has no one to take care of her. The television provides the illusion of a presence; the cell phone she clutches gives access to other people; and Kildegården is staffed with people who can monitor her. After her stroke, Ms. Petersen needs people around her; this is in direct opposition to her former everyday life in which she preferred to live alone.

What we see is that, by causing Ms. Petersen to feel fatigue, the stroke also makes her aware of how this fatigue is essentially a manifestation of the stroke – something that could have killed her. The repositioning of her fatigue in relation to sleep thus plays a part in the way she is not only tired of being fatigued, but essentially also afraid of the sensation. Fatigue is untrustworthy and highlights the burden of being, but it is also not like sleep in which this burden disappears, but a place where the threat of not waking is a constant threat. By resisting fatigue, Ms. Petersen thus signifies a wish to not surrender to what the stroke presented her with: namely, an explicit path towards death.

In a somewhat similar case, another of my informants, Mrs. Albertsen, a 49-year-old married woman, explains how the stroke event altered her sense of her own being, and how the Angst of another stroke is constantly present:

(Mrs. Albertsen) The fear is there. It is not so long ago, but yes, the fear is there...it doesn’t take up that much space, but yes, it’s there. (...) Also because I know that both my dad and my brother...my brother just had one, where I thought, “No, goddamnit”. So yes, I’m constantly reminded of it, and if it wasn’t me then it was Palle (her brother). He has had multiple [strokes], not

just in his brain, but also in his heart, so of course it is something that takes up a lot of space. It also makes you think differently about a lot of things, like, “Maybe you shouldn’t wait to get that done or get this done”. I can feel that there are some things where I have begun to think, “We’re not waiting to get this done, we’re just going to do it.

The Angst about another stroke that might debilitate her or end her life causes Mrs. Albertsen to feel differently about her own temporality. In a sense, the stroke makes the present *present*, and postponing things becomes more difficult for her, as she is forced to live in the present, taking care of the things she feels she must take care of. Many of these things, however, are directly related to a kind of dismantling of herself. After the quote above, she continues and explains:

(MA): *What are those things you feel you need to get done?*

(Mrs. Albertsen) It might be travelling, getting some papers organized, talking through some things. Talking through some things is sometimes very difficult, especially for your partner. It’s like thoughts that never had the same weight as they have now. So, telling your partner some things, but also your kids...there are some things that are different.

(MA): *Why do you think it is more difficult for your partner to talk about these things?*

(Mrs. Albertsen) I think I also had a hard time talking about these things before I became ill. Then maybe these things have suddenly become extremely important to me, [and they] don’t have the same importance for him. For instance, I said to Per (her husband), “If I die, will you remarry?”, and I thought (*she begins to cry*) (...) which I thought would be completely natural because he shouldn’t sit there as...but where he was just saying, “I don’t want to talk about that”. I could understand him, but for me it was just important to say that it’s okay with me if he does it. Telling my kids how much I love them... (*long pause with Mrs. Albertsen crying*)

We can see how Mrs. Albertsen has been presented with a completely different way of being than before, and that her way of being is in conflict with how her husband is experiencing his own life. Several factors are at stake here: her brother’s and her father’s strokes, her own stroke and, as she tells me later, a fear that she may be particularly susceptible to strokes, which prompts her to have a genetic test taken in a month’s time. The process of dismantling is further problematized by her fatigue, which causes her to not be able to do all the things that she feels are necessary. Coupled with a sense of constant forgetfulness, Mrs. Albertsen expresses that she is afraid that she might forget something in the process as well. In that sense, one could argue that Mrs. Albertsen is afraid to forget

what might be important in the future; even (and maybe specifically) in a future without her. Mrs. Albertsen and her thoughts about her life are particularly noteworthy, as she constantly makes me aware of how it is the fatigue – and not the partial paralysis of her right hand – that makes her feel incapable of coping with everyday life. As she explains it, she would rather eliminate her fatigue than the partial numbness in her hand. This statement underscores how fatigue encapsulates her entire being, making it difficult to get accustomed to her new everyday life. The fatigue does not allow her to forget her stroke or her susceptibility to future strokes, but it constantly reminds her that she cannot move beyond the stroke as well as about her own mortality – which is similar to Ms. Petersen. But in Mrs. Albertsen's case, we can supplement the existential analysis with a social dimension because she is worried about her children losing their mother and her husband losing his wife. She is fully aware that she holds a significant place in their lives – as they have a significant place in hers – and the stroke has further emphasized this relationship. Nonetheless, her husband is reluctant to discuss what would happen if she died and attempts to help her return to their everyday life. From an existentialist point of view, this would entail forgetting her finitude. But this is not possible for Mrs. Albertsen: through her daily sense of fatigue and forgetfulness, she is constantly reminded of her stroke – and, by association, of her own death and the loss that would follow it.

Experiencing immense difficulty in “returning” to everyday life after her stroke, Mrs. Herschel, a woman of 47 years, represents how everyday life may be radically altered by the event of a stroke. Mrs. Herschel had her stroke shortly after she was informed of her husband's diagnosis with colorectal cancer. At that time, she had been taking a leave of absence from work for four months due to stress-related issues. She told me later that, when she eventually had the stroke, she felt like everything became too much to handle. After undergoing medical treatment and physical therapy at Glostrup Hospital, she was discharged and experienced a period of illness at the same time as her husband. By the time I interviewed Mrs. Herschel, her husband had recovered and returned to work, but she was still struggling with the aftereffects of her stroke, manifested almost entirely in an immense and overwhelming sense of fatigue:

(Mrs. Herschel) I think about everything, and Mr. Herschel doesn't think about jack shit. He has had surgery and has become well, and he thinks that I have also become well, which I guess I have,

but my head just looks differently at everything. That's been very difficult because it culminates at home. I think it's all been a mess at work, and it's been a mess at home. In that way, until he received his diagnosis and until he went through surgery, I feel that we were following each other, and we shared our concerns...we had the united approach that we just had to get on, but he is just much more like that than I am. He doesn't really think much about it, and if there's food in the refrigerator and everything is as usual...we mow the lawn, but I just can't help thinking about things. I analyze things so much, and I think it's really annoying. (...)

Mrs. Herschel's life changed after the stroke, and she constantly attempts to deal with the expectations of returning to her former everyday life, and her inability to do so because of how the stroke altered her perceptions. Several things are at stake here. First of all, as she explains it, she feels like the stroke opened up a Pandora's box, which has made her doubt many of her decisions in life; second, opening this box means that she cannot return to her former everyday life. She feels alienated from her husband and their previous everyday life together, which causes her to feel lonely:

(Mrs. Herschel) I don't think that anything has changed from an outside perspective. If you look at it from the outside, from Mr. Herschel's point of view, nothing has changed. We do exactly the same things we have always done. We live in a nice house, pay our bills on time and are generally very decent folks, so I don't think that when you view it from the outside that anything has changed. I think it's only up here (*points at her head*). (...) It's just like he (Mr. Herschel) is not present in any way...he isn't. He never has been, so again there's nothing new, it's just that I have gotten some different needs, I guess. But I try to meet the needs with friends, and I think that's okay, but I often think about us, two people sitting on the couch each night, it's goddamn lonely. I think it's been like that all the time, I just don't think I have been able to see it. But I often think that I wish I couldn't see it, because I think it just makes matters worse...it would have been easier if I didn't notice it.

This change in perspective that Mrs. Herschel describes is also recognizable in my interviews with both Ms. Petersen and Mrs. Albertsen, although Mrs. Herschel seems to be very aware of what she is going through. Interestingly enough, it is not only her fatigue that positions itself between her and the return to her previous everyday life – it is also the fact that the stroke caused her to take stock of her life. The result is that, even though she wishes she could return, this would not be possible because the Pandora's box has been opened.

These three informants handle their strokes within a framework of temporality and represent the same problem of how to return to everyday life. Mrs. Albertsen and Ms.

Petersen are focused on the present and the future – being anxious about what will happen, and how to cope with an everyday life in which they do not manage to recapture their former selves. In their cases, their former selves – i.e., the person they were before the stroke – becomes a point of reference to which they would prefer to return whereas, for Mrs. Herschel, her former self is a figure of blissful ignorance. Thus, in Mrs. Herschel's case, the future, the present and especially the past are thrown into the air during the interview as she retrospectively tries to construct how she got to where she is now. She is disappointed by her husband, who she expected to go through a similar transformation following his experience with colorectal cancer. Yet her husband sticks to the same old routines and seems to have returned to his everyday life, doing what he has always done. In a strange sense, his return to everyday life and the way he follows the routines of his previous everyday life are disturbing to Mrs. Herschel: her former everyday life is put directly in front of her. But in doing so, the emptiness of that life is also conveyed; Mrs. Herschel cannot return to this life – and is not sure she wants to.

From an existentialist point of view, we can see that the being of these three informants is placed in front of them, demanding that it be taken up. This is a being tied to a former self, and it is closely connected to everyday life. Fatigue seems to make their attempts to return to this former self extremely difficult, and it becomes a constant reminder of the disruption of the stroke: of all the things that cannot be done anymore, and all the things that a retrospectively constructed self was capable of doing. These narratives all point to a reconstruction of the world as *zuhandensein*: the point in time when one is not aware of the chair gnawing into one's bottom, does not experience the weight of one's paralyzed arm or notice the gradual deterioration of things; when one's relation to the world allows the finitude of one's own existence to disappear, and when one is not aware of the burden of existence. Everyday life is exactly this place where our existence is not placed in front of us and, amid the disruption, one's inability to meet the retrospectively constructed expectations of this everyday life produces a sense of being out of sync or in chaos while it also reveals the world as *vorhandensein*. In essence, the disruption and fatigue described by my informants hinders their return to everyday life.

In this chapter thus far, we have seen how the feeling of fatigue that follows a stroke may be a constant reminder of the stroke's threat to one's life. In relation to stroke, fatigue represents the fact that one's being is a being moving towards death. To cope with this realization, the two obvious philosophical possibilities are either a forgetfulness of being or taking up one's being towards death (Heidegger 1962 [1927]-a, 69). The third way to cope with the realization, which is highly reminiscent of the first possibility, is through a re-appropriation of one's everyday life, so that the fatigue becomes less alienating and is allowed a certain space. Then, it can transition from being an actual threat to becoming an after-effect, which is ultimately just another condition of life. This way of dealing with the fatigue that follows a stroke is what I most often encountered in my fieldwork among informants who had had a stroke a long time ago and succeeded in incorporating the stroke into their everyday lives. The question now is how fatigue is situated within this everyday life, and to what extent it is incorporated or excluded from the re-appropriation of everyday life; this is addressed in the next section.

Fatigue as a *Stimmung*

While many of my informants who recently had a stroke – particularly, the informants under age 65 with fatigue – experienced the stroke and their subsequent fatigue as a violent disruption of everyday life, the informants who had a stroke years ago – and still experience fatigue – expressed a different approach to everyday life. In regulated systems of order and predictability, much of their everyday lives have been arranged – alas, with sleep as the unpredictable, yet indulged, component.

In this chapter, I want to touch upon how it is not always factors such as physical capability, age, matrimonial status etc. that may cause one to experience an inability of getting a new everyday life, but rather that this is tied to the way in which fatigue, as an acknowledged deficit, is incorporated within this life. In existentialist terms, I argue that when fatigue is incorporated as an essential part of one's being, then the conflict between being and everyday life is resolved. When fatigue simply becomes a part of being, there is no need to assume one's being, as Lévinas suggests; instead, fatigue becomes a part of being itself. Building upon Lars Svendsen's existentialist, Heideggerian approach to boredom – in which boredom is presented as a certain *stimmung* that summons a relation

to one's being where events or things are robbed of meaning – I approach fatigue in a similar fashion. It is important to highlight that this is not equivalent to the *zuhandensein* or *vorhandensein* analysis of everyday life: things in the *stimmung* of boredom *do* appear, and events are experienced as events (Svendsen 2004, 115). Rather, a *stimmung* is the filter through which one experiences one's being-in-the-world. Whereas things and events disappear in the "*zuhandensein*ness" of everyday life, boredom makes things and events appear in relation to one's *stimmung*; in essence, we are never outside of a *stimmung*. But this does not mean that all things and events always appear to us; rather, it means that some things *do* appear as a result of the facticity or thrownness of our being. A *stimmung* may provide us with an experience of space and time: in the *stimmung* of boredom, for example, space and time are empty and devoid of meaning; the objects in one's surroundings are indifferent, and the time one spends in the surroundings is unbearably slow, bordering on being stuck. The question is how to fill this time and space with meaning – a question that is impossible to answer within the *stimmung* of boredom. As often presented in existential philosophy – and as Svendsen also shows – being bored is not a state of not having anything to do; rather, it is being unable to see other things due to the *stimmung* of boredom. Svendsen presents boredom as a *stimmung* that may highlight the potentialities of being – much more than the everyday life in which we live. In that sense, and in its ultimate potentiality, boredom is also a road to the awakening of one's unique Dasein (Svendsen 2004, 122)²⁰.

Before moving from the *stimmung* of boredom to what I call the *stimmung* of fatigue, I must stress how my informants often expressed a sense of boredom in addition to their fatigue. Sometimes, fatigue is welcomed as a break from this boredom while, at other times, it is presented as the cause of the boredom; the fatigue prevents the occurrence of another *stimmung* – perhaps that of elation. Because, as Svendsen argues, the *stimmung* is a result of our thrownness into the world, it is not possible to consciously get rid of it – it orders our perception of the world, but we may suspend it with sleep. On our way to this suspension in sleep, fatigue presents the burden of our being, now being slowly relieved.

²⁰ According to Heidegger, there are two types of boredom: one in which a person is being bored with something (*Gelangweiltwerden von etwas*); and one in which a person is bored with oneself by something (*Sichlangweilen bei etwas*) (Svendsen 2004, 125). For Heidegger, the latter type of boredom is truly existential.

In the following paragraphs, I use my fieldwork findings to present how fatigue can be considered a *stimmung*. When it becomes a chronic feature of existence, a *stimmung* can be difficult to see; thus, as the filter through which one sees and experiences the world, it is a difficult matter to approach. Being in being, one might recognize that one is entrenched in the *stimmung*, yet it does not reveal the specifics of how this is so; i.e., how the *stimmung* plays out in actual everyday life. To a certain extent, it seems as though a *stimmung* feeds on and lives from this ignorance, as the first step towards eradicating the *stimmung* would be to suddenly realize that it is structuring one's perception.

Paradoxically, a *stimmung* most obviously reveals its grip on one's existence through its radicalism; in that sense, it is, as Heidegger says, a possibility. In my fieldwork, however, the fatigue with which my informants lived in their everyday lives mostly presented itself through their significant others. Not that the informants themselves did not say they were fatigued – they just did not know why, from what or how they became fatigued. But their spouses – keen observers of every minute detail in their significant others' lives – provided numerous interpretations and suggestions as to why, from what and how their spouses were so fatigued. Thus, in all the cases that follow, I go against convention and structure my analysis based on the spouses' narratives and their experiences with their afflicted husbands and wives.

Mrs. Nielsen has been taking care of Mr. Nielsen ever since he had a stroke in the autumn of 1996, shortly after he retired from working as a stonemason. As a result of the stroke, Mr. Nielsen suffers from partial paralysis on his left side, but regained much of his functionality after intensive training at a rehabilitation therapy center in Montebello, Spain. At the time of my fieldwork, he is capable of walking short distances with a cane, but prefers not to. For most of the day, he sits in a specially-made chair, alternately watching TV and sleeping. When I ask Mr. Nielsen to describe his everyday life, his wife immediately says:

(Mrs. Nielsen) (*points her finger at the television*) Television... as soon as he has his breakfast, the first thing Mr. Nielsen does is turn on the television. Sometimes, I turn it on because I want to see "Godmorgen Danmark"²¹ at nine, but Mr. Nielsen can sit and watch it all day long. He can't endure reading... it's difficult for him to concentrate. He has a good chair that he can recline in. (...) Now that you're here, he's not sleeping, but otherwise, it would be certain that he would be

²¹ A Danish morning news and talk show.

nodding his head right now. He sleeps...an hour during late mornings – right, Mr. Nielsen? (*Mr. Nielsen responds, “Yes.”*) And then he sleeps half an hour here and half an hour there. I came home last night at around half past nine, and he had just slept. If I call and ask him, “Have you just slept?”, he answers, “Yes.” He sleeps so much, and he sleeps all through the night as well.

Mrs. Nielsen is obviously frustrated by Mr. Nielsen’s sleep patterns, although their everyday life has been arranged to accommodate Mr. Nielsen’s fatigue without impacting Mrs. Nielsen too much. Nevertheless, Mrs. Nielsen’s reaction clearly shows how his limited physical capabilities – along with his experience of fatigue – influence their shared everyday life. She continues:

(Mrs. Nielsen) I guess Mr. Nielsen – don’t get me wrong – is actually living a rather easy life. The only thing he has to focus on is eating, sleeping and drinking, and following me when I tell him we have to go somewhere.

(MA) *How about daily chores?*

(Mrs. Nielsen) Zip...nothing at all. Making things work and so on, but it’s not that he doesn’t think about his existence...our existence...he does, but it’s not something he says anything about. I’ve become so used to the fact that he can’t contribute anything, so I catch myself saying “Arrrrrgh” because there’s nothing coming from Mr. Nielsen. So, in a certain way, Mr. Nielsen is hit pretty hard because it’s not something he does to be mean. It’s probably something that is difficult to...I guess you have to try it.

During the interview, Mr. Nielsen says very little; when he does, it primarily revolves around the routines he has incorporated into his everyday life, which are manifested in his fixed attention to looking for the mailman, who arrives during the interview. Mrs. Nielsen believes his general inattentiveness has caused them to lose much of their social network, and it makes it more difficult for her to relate to him. This is further exemplified by Mrs. Nielsen turning off the TV when I arrive, as she tells me that Mr. Nielsen would not talk to me if it was on. All in all, Mrs. Nielsen exudes the experience of someone who is sharing an existence with a person who, in a phenomenological sense, no longer shares her lifeworld (Merleau-Ponty and Husserl 2002, 32). In Mrs. Nielsen’s view, she is living a life that is very different than what she previously imagined, and Mr. Nielsen’s constant fatigue – along with his inability to share any household chores with her – separates them from each other. She mentions that she has often thought about divorcing Mr. Nielsen but she cannot make herself do it, as she does not know who would take care of him. Mrs.

Nielsen has a persistent sense of wishing to “opt out” in order not to be dragged down; during our interview, she often turns her anger towards the government’s multiple cutbacks on public spending, which impact stroke patients and do not make their shared life any easier. Whenever she begins this tirade, Mr. Nielsen supports her, and they are momentarily joined in the project of complaining about these cutbacks until Mrs. Nielsen mentions that she does not think Mr. Nielsen considers all the issues that she has to handle alone. All in all, one could argue that the stimmung of Mr. Nielsen is most directly expressed in Mrs. Nielsen’s frustrations about being “dragged into” such a life. She sees his fatigue and, during the interviews, it seems obvious that she is the one most annoyed by it. Mr. Nielsen, on the other hand, expresses little complaint, although he does recognize it as a problem. When it does pose a problem for Mr. Nielsen, it is when his routine is altered in such way that does not allow for him to be fatigued. In that sense, certain social gatherings are fine as long as they do not interrupt this routine too much. For example, Mrs. Nielsen talks about a holiday arranged by a stroke foundation that suited them quite well:

(Mrs. Nielsen) It has to be planned in such a way so that there are a lot of breaks. We were at Sønder Felding (once each year) for a period of six to seven years – right, Mr. Nielsen? – and that was for people who had had strokes, but it had been planned and arranged with many long breaks and a good long lunch, where we had time for an afternoon nap afterwards, and then nobody wept because people did not attend one afternoon. I often went alone because Mr. Nielsen was sleeping. It’s because anyone who has to do anything with people who have had a stroke know that the one up there (points to her head) is not a hundred percent functioning. You need rest.

From this quote, we get a good indication that there are many things that have to be taken into consideration in order for Mr. Nielsen to feel as though his condition is accommodated. But Mrs. Nielsen is annoyed by the many special everyday concerns for Mr. Nielsen; she feels inadequate when she cannot comply with them. And Mr. Nielsen becomes very angry when these concerns are not followed, as his routine is potentially hindered:

(Mrs. Nielsen) ...you know if it’s not planned and placed according to Mr. Nielsen’s disability, then it’s me who’s an idiot. Then the homecare nurse will arrive or the kids, and they’ll throw something out into the hall, and then Mr. Nielsen arrives, and I can tell you he gets mad. They’re not used to it...that you can’t throw anything into the hallway because Mr. Nielsen can’t get through. That’s how our everyday life is. You constantly have to arrange things like this, and you can’t have

everything sitting in the closet just at nose height, and I know that Mr. Nielsen can stand up and lift an arm...well, it doesn't have anything to do with fatigue – well, yes...mental fatigue.

The phenomenological and existentialist idea that resistance may pull one out of one's everyday life by making certain things appear seems to be apparent in this quote. Every time Mr. Nielsen is confronted by obstacles to his being, he is challenged by his current situation: a situation in which his fatigue has become the primary matter of concern, and where he is – in Lévinas' words – not capable of living up to his being. The objects of hindrance in the hallway essentially pull Mr. Nielsen out of his *stimmung*, but they do not do it in a way that allows him to escape his *stimmung*; rather, they are presented as obstacles to the continuation of his *stimmung*. Just like a sleepwalker – who walks through a room and trips on some object – may be angry at whoever left the object in his way, so may the *stimmung* direct its annoyance at its discontinuation of something else, only to sink back onto itself.

For Mr. Nielsen, fatigue has become such an essential part of his life – and how he experiences his everyday life – that everything revolves around the fatigue, including his material surroundings. This is obvious to his wife, who does her best to pull Mr. Nielsen out of his *stimmung* – sometimes successfully, but often to no avail, as the *stimmung* is constitutive of Mr. Nielsen's everyday life and routines. Although Mr. Nielsen may have done his best to fight the sensation of fatigue, I conclude that it has taken root and, as Mrs. and Mr. Nielsen argue, it does not make sense to constantly bicker about how one ought to fight the stroke's consequences. As I argue later in the chapter “The Regimes of Hope”, the idea of “the fight” actually alienates my informants more than it helps them – they feel inadequate because they have failed to do what others have succeeded in doing – i.e., combating their fatigue and other after-effects of the stroke, only to become more enlightened, as is shown by neurologist Jill B. Taylor in the bestseller *My Stroke of Insight* (Taylor 2006).

By looking at fatigue as a *stimmung*, I have attempted to provide an analysis in which a *stimmung* – much like the phenomenological concept of intentionality – is the gateway through which one experiences and views one's being. One is always in a *stimmung*, but in Mr. Nielsen's case, the specific *stimmung* has become his way of life; it interferes with his

everyday life, and he is stuck with a condition that makes it impossible to live his previous everyday life. His new everyday life is designed and arranged so that the noise of fatigue as resistance will be drowned out, but in doing so, it instead becomes the center of everyday life for him and his wife.

The Narratives of Fatigue

Le moment est venu de relier les deux études indépendantes qui précèdent et de mettre à l'épreuve mon hypothèse de base, à savoir qu'il existe entre l'activité de raconter une histoire et le caractère temporel de l'expérience humaine une corrélation qui n'est pas purement accidentelle, mais présente une forme de nécessité transculturelle. Ou, pour le dire autrement: *que le temps deviant temps humain dans la mesure où il est articulé sur un mode narratif, et que le récit atteint sa signification plénière quand il deviant une condition de l'existence temporelle*²². (Ricoeur 1991 [1983], 105)

In the previous chapter, I touched upon how my informants incorporated their experiences of stroke and fatigue into their narratives, and how these factors play an important role in terms of how they experience their own being. At this point, it should be obvious that fatigue has a presence as a bodily phenomenon that can be experienced and which goes beyond one's immediate presence. As I have argued throughout this thesis, both the past and the future are integral to the experience of fatigue: the future is that which is constantly at stake when experiencing fatigue, while the past serves as a what I would call "a constant memory of comparison".

In this chapter, I present a more thorough reading of how these temporalities become incorporated within the narratives of everyday life; specifically, I focus on the construction of those narratives in which fatigue and stroke play an essential part. In order to analyze how temporalities are entangled in the construction of a narrative of fatigue, I employ the analytical approach to narratives developed by French philosopher Paul Ricoeur.

However, his work is of little epistemic value if not presented alongside his conceptualization of the relation between subjectivity and language; thus, I must first give a very brief overview of Ricoeur's philosophy, accompanied by a more thorough introduction to his concept of *mimesis*, which informs his approach to narrative theory and, accordingly, my approach as well.

Ricoeur is probably most famous for bringing hermeneutics back to the forefront of modern philosophy; he argues that a hermeneutical approach to linguistics or language

²² Translated as "The moment has come to join together the two preceding independent studies and test my basic hypothesis that between the activity of narrating a story and the temporal character of human experience there exists a correlation that is not merely accidental but that presents a transcultural form of necessity. To put it another way, *time becomes human to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence*". (Ricoeur 1984, 52)

paves the way for understanding human subjectivity. He does this mainly by arguing that human subjectivity is intrinsically tied to linguistics; this implies that, as a prerequisite for human subjectivity, *meaning* is constantly created within a textual and thus linguistic framework. It is within this textual framework – which is essentially the framework of language – that the problematic of subjectivity and thereby existence unfolds. Language articulates human subjectivity and, by examining language and employing narrative theory, Ricoeur provides analytical tools that allow us to discern how everyday life can be presented as meaningful. Let us now take a closer look at Ricoeur’s conceptualization of the subject; it is here that the subjectivity to which I have been referring is contained.

Drawing upon the phenomenological tradition, Ricoeur starts by situating the subject as an embodied being. This phenomenological approach deviates from the Cartesian idea of a subject, which implies an understanding of the subject as something other than a rational being, able to deduce his existence and self-understanding from individual, monological thought. Instead, Ricoeur proposes that our subjective self-understanding is produced through an imaginative interpretation of our embodied being-in-the-world. This means that subjectivity is tied to language, as interpretation implies a language of interpretation; thus, Ricoeur suggests that it is through language that we may be able to discover the *problematic of existence* – i.e., our being. However, Ricoeur points out that this quest must be undertaken carefully, as language and discourse may not only reveal but also conceal the nature of being. All that being said, Ricoeur is not post-modern in the sense of viewing subjectivity solely as an effect of language. To understand this, we must examine in further detail Ricoeur’s views on the concept of the embodied subject. His work *Freedom and Nature: The Voluntary and The Involuntary* (Ricoeur 1966) provides a good sense of his founding conceptualizations of the subject (Ricoeur 2002, 17). First of all, as human bodily creatures, we are subject to certain constraints; on the other hand, we inhibit voluntariness, which is necessary for us to perceive ourselves as agents of action. This relation between voluntariness and involuntariness corresponds to a relation between our being in the phenomenal world and the material world, first of by which we free ourselves from the laws of nature through our actions (Kaplan 2003, 77-78). Our selfhood must then be intersubjectively constituted and, as such, Ricoeur argues that there is no such thing as a “self”. Selfhood is the grasp of oneself as something that is in a certain situation, and that

has both a material and phenomenological character. One is thus linked in both time and place to others as well as to the history of which one is part. To grasp oneself is to ask the question, “Who am I?” – something that will essentially remain unanswerable, as *I* am the one seeking the answer. In that sense, the search for selfhood is somewhat dialectical, and the hermeneutical circularity of the question positions the physical body not as a distinct entity but instead as a fundamental predicament. In other words, my body cannot be separated from the situation wherein I perceive something; rather, the situation of my body, through which I perceive, must be intrinsic to the analysis of my perception. My knowledge of the world is essentially open for interpretation, and thus also my knowledge of my own existence – in effect, we are never quite certain of ourselves as human beings. Yet in understanding/positioning ourselves as a subject in the world, we navigate within a temporal dimension of selfhood with different orders of time. It is the breakdown of these temporal dimensions of the self’s narrative – i.e., the construction of subjectivity – that Ricoeur approaches through narrative theory; Ricoeur refers to this as *a hermeneutics of distance* (Kaplan 2003, 200).

Ricoeur’s hermeneutics of distance is prevalent in his concept of the threefold *mimesis*, which is a significant methodological feature in one of his most famous works, *Temps et récit* (Ricoeur 1991 [1983]). The mimesis analysis is based on how humans create narratives to construct meaning, and how these narratives are intrinsically tied to temporality. To that extent, narratives go beyond a “normal” description of time as the experience of linear succession (i.e., one minute following another), and instead express a phenomenological time in which time itself is experienced through its threefold dimensions: past, present and future. For Ricoeur, this means that we experience time through a linear succession of time – what he calls cosmological time – as well as in relation to what has happened, what is happening and what will happen. According to Ricoeur, these two notions of time – cosmological and phenomenological – comprise the unity of time and are thus not in opposition to each other. Ricoeur argues that, to philosophically understand human existence, one concept of time cannot be excluded in favor of the other; we must understand how they feature in a shared temporal framework. Ricoeur argues that everyday life is comprised of narratives; these narratives often have a strong suggestion of causality, which avoids the meaningless succession of events. Thus, when telling a story

about everyday life, one is choosing what to tell, how to tell it and how to connect one's choices in order to create a cohesive narrative. How this act of narration occurs becomes apparent if we take a closer look at the mimesis model.

The most accessible way to understand the mimesis model is to look at it from the point of view of a literary work, where there is a relation between the *Work*, the *World* and the *Interpreter*. In this sense, the threefold mimesis model can basically be summed up as: mimesis 1 – *prefiguration*; mimesis 2 – *configuration*; and mimesis 3 – *refiguration*.

Mimesis 1 is the prefigured basis that underlies the logic of the narration's plot. For the Work to be read, it must rely on the ways in which our being-in-the-world is presented to us in our everyday lives, as it relates to how we understand the world. This is possible because, as human beings, our experience of the world is always already ordered, or prefigured, in a certain way. In effect, the Work plays on our expectations and experiences.

Mimesis 2, on the other hand, represents the ordering of the plot's events, and thus an entrance into the World of the Work. Mimesis 2 is essentially a kind of narrative "emplotment" in which an imaginative order creates and sustains a plot. The emplotment makes all of the story's elements feasible within the plot; it mediates between the story's objects and subjects, configuring their place within the network of the plot. Basically, the emplotment makes each subject or object part of the narrative with its own situated and, not least of all, meaningful position in the overall goal of advancing the plot. No matter how heterogeneous these elements of the narrative may seem, their apparent internal cohesiveness – configured within the narrative – allows them to co-exist in a meaningful way. In effect, the temporal linearity of the narrative may be altered to ensure such cohesiveness; this is the case when, for instance, a narrative begins with what would usually be considered the end in a temporally linear structure. Thus, the narrative operates within a logic that is not temporally linear, but which aims to endow the connections of the narrative's elements with a certain necessity; this is essentially emplotment. It creates the necessity for one thing after another to be narrated, although these things may seem far away from each other in time. In this sense, the narrative is allowed to create a

meaning that goes beyond the linearity of time and to sustain an almost invisible necessity in two events that follow each other, even though the two events themselves may seem somewhat apart. The narrative portrays how things “had to happen” for the plot to be as it is and, in doing so, meaning is created.

With the final mimesis of refiguration, we find that this – just as much as it is the name of the interpretation and process of experience that emerges at the moment we receive the Work – is the road back to mimesis 1. Mimesis 3 takes the imaginative perspectives from mimesis 2 and integrates them into lived experience: they become part of one’s identity and self-understanding. A hypothesis in mimesis 2 may thus become a fact in mimesis 3 by, for example, dating the hypothesis within the narrative, placing an emphasis on the hypothesis as a lived experience that is important to one’s self. As a cyclical process, the mimesis is never finished; basically, due to the fact that new life circumstances constantly alter and change the narrative – which calls for a new interpretation. Suddenly, on the basis of our altered circumstances and new experiences, new networks of interpretation between subjects and objects are realized, and they are seized to become part of one’s identity formation. Events from the past are then prefigured, configured and refigured to match the new circumstances. One might ask, “Why this is so? Why do one’s circumstances have to be definitive for the narrative to be created?” For Ricoeur, the answer is obvious: a narrative lives by cohesion and structure, and a narrative that does not consider the plot (or the contemporaneous state of affairs) thus lacks such a structure. Instead, it becomes incohesive in its inability to match cosmological time and is thus incapable of providing meaning – which is the most crucial aspect of Ricoeur’s notion of subjectivity.

I cannot list all the philosophers and social scientists who have engaged in the use of narratives, but I do want to draw attention here to both Arthur Frank and Arthur Kleinman; specifically, due to their use of narratives in their analyses of the experience of illness. Neither of them attains the breadth of Ricoeur’s theory, yet they both approach the structure of the narrative as something that may allow the social scientist to grasp the experiences of the chronically ill. I now outline some of Frank’s findings to enlighten the reader on how a narrative approach to illness presents itself in practice.

In his book *The Wounded Storyteller* (Frank 1995), Frank presents three types of illness narratives; he argues that these are often encountered when dealing with people who are suffering or recovering from an illness. Frank's illness narratives should not be confused with Ricoeur's narrative theory because of the similarity in taxonomy – Frank does not present the process of creating narratives as much as he describes the result of the narratives. These results are typologized into “restitution”, “quest” and “chaos” narratives. Whereas the restitution narrative follows the narrative often encountered with a minor illness, such as the flu – namely, locating the virus, getting treatment, rest or medicine and finally getting better – the quest narrative is somewhat opposite to the “return” of the restitution narrative; it is the integration of the experience of the illness into a retrospective as well as prospective dimension. An illustrative example could be a stress-related illness, which causes one to reconsider the pace and direction of one's life, potentially altering it. In essence, the quest narrative could be interpreted as an eye-opener; it offers a premonition about what might happen if one does not alter one's course in life. Finally, the chaos narrative is the direct opposite of the restitution narrative. It is devoid of a route, a plot or even a meaningful beginning or end. It is essentially a narrative that is difficult to understand, as there is no predictability or attempt to create a common thread throughout the narrative. As sociologist Sarah Nettleton et al. argue in “Enigmatic Illness: Narratives of Patients who Live with Medically Unexplained Symptoms” (Nettleton et al. 2004), chaos narratives are often found among patients who live with undiagnosed illnesses. Thus, the chaos narrative – far from having what Cheryl Mattingly (Mattingly and Garro 2000, 18) would call the “power of the narrative”; namely, connotative language and shared imagery – is a narrative without control and without the time to create any kind of narrative stability. It is interesting to incorporate the chaos narrative into Ricoeur's threefold mimesis, as the chaos narrative seems to almost take the narrative itself hostage. In Ricouerian terms, the chaos narrative robs one of a self-formation, unless the chaos narrative itself becomes the locus of this formation. In that sense, the plot of the chaos narrative is that no plot can be made. I do not intend to delve deeper into this problematic, but it is nevertheless interesting to note how a chaos narrative, being devoid of meaning, may itself be the meaning within self-formation.

Many of my interviews began with me asking the informants to tell me something about themselves. In some cases, they offered very brief comments, such as, “Well, I’m just an ordinary person, I guess”, whereas others would provide me with long stories about their lives. What caught my attention, however, was that the narratives about their strokes were often extremely descriptive and ordered; the following example represents such a narrative. As told by Mr. Olson’s wife, it shows how the story of his stroke has been told over and over again:

(Mrs. Olson) It’s a strange thing, but it was Friday the 11th of February, and our son was here, and we were about to have some lovely food – it was steak tartare – so we were going to have a glass of red wine along with that. So I arranged the plates, but you were very fidgety (*she looks at Mr. Olson*), you were all over the place, and then suddenly you sat down in here (the living room), and then our son called me. Then Mr. Olson sat like this (*portrays a lopsided position*), with your mouth and leg hanging down.

(Mr. Olson) On my left side, wasn’t it?

(Mrs. Olson) Then he said, “It’s a strange thing”, you know he could speak: “It’s like my jaw is dislocated.”

(Mr. Olson) But that was just on the other side, wasn’t it?

(Mrs. Olson) Yes, it was the opposite side, and that was to a certain extent also correct, because in May 2008 we went to Rigshospitalet (a large hospital in Denmark) and a constriction of arteries was identified, and it was apparently the one that had darted up into his brain...that’s how it happened. But our son was rather quick and called for an ambulance, and then I said, “We have to go to Rigshospitalet”, because that’s what they said back then, but they don’t do that – the paramedics – and then we were driven to Glostrup. But it’s an ugly ordeal – a very ugly ordeal.

As outlined later in this thesis, the narratives surrounding a stroke tend to be communal. But what is of particular interest in the narrative above is the sudden shift in time. Mrs. Olson begins by talking about how the evening of the stroke progressed, going through the events meticulously and chronologically. However, when the question arises about where the stroke was first physically detectable, Mrs. Olson incorporates another time point into her narrative. This time point serves to provide an explanation for the event of the stroke – namely, Mr. Olson’s constriction of arteries and the identification of this problem some years earlier. In her narrative, Mrs. Olson manages to connect a previous event with the event of the stroke, even though she claims that the constriction of Mr. Olson’s arteries

was detected on the right side of his jaw, whereas she also claims that the stroke was physically detectable on the left side of his jaw. This fact loses attention within the overall narration due to the explanation that Mrs. Olson offers about the mythos of the stroke. In essence, the retrospective dimension of the narration becomes the overall figure to explain the event of the stroke – as a sort of premonition, the stroke was always inherently present in the constriction of the arteries. Mirroring the structure of ancient Greek tragedies, the subtle or invisible warnings suggested at the beginning of the plot only become fully apparent at the end. The narrative essentially shows how a past event foretold the plot of the narration; i.e., the end was always present at the beginning. To that extent, the narration also represents a failed incorporation of the warning, which alludes to the possibility that the future event of the stroke could have been avoided if one had incorporated this warning into everyday life.

The excerpt also shows how different heterogeneous elements become tied together, even though their significance to the narration is slightly obscured. For instance, the steak tartare that the family was supposed to eat along with a glass of red wine is a piece of information that does not immediately seem to inform anything with regard to the overall plot. But it could be analyzed in relation to mimesis 1, in which the narration establishes a former prefigured basis. Although steak tartare is not an item commonly found on Danish dinner plates, the information creates the sense of a specific dining situation and establishes a background through which the shock of the stroke permeates.

All the same, the narrative does not correspond very neatly with the narrative typologies presented by Frank. While Mr. Olson claims that he feels fine, Mrs. Olson is distinctly aware that something has changed with him – something that she constantly attempts to put her finger on, but cannot really identify; I describe this later in “The Narrative as Communal”. Either way, Mr. Olson’s narrative is not one of “restitution” or “chaos” nor is it a “quest”. Different pre-stroke and post-stroke “signs” are taken into consideration by the couple during their narration. However, the changes in their everyday practices are not presented as willful; rather, they are changes that have been forced upon them. But identifying these changes – i.e., placing them in a meaningful relation to their notion of a stroke – is a struggle. This highlights how, in any narrative, the structure of mimesis 1 is

essentially constitutive for the configuration of mimesis 2 and eventually the re-configuration of mimesis 3. Mr. and Mrs. Olson struggle to gain meaning from their pre-conceptions of what a stroke is, the information they receive about strokes in general and Mr. Olson's actual experience of a stroke.

In another example, Mrs. Nielsen talks about Mr. Nielsen's stroke and, in doing so, she produces a very powerful narrative. The reason for her construction of such a powerful narrative is illuminated later in the interview when Mrs. Nielsen explains that they have "performed" the narrative a couple of times for nursing students, due to Mrs. Nielsen's chairmanship of a local stroke organization. She says:

(Mrs. Nielsen) He couldn't even sit when he got hit – it was like a toddler. Then he had what I would call an idiotic expression, and I thought, "Wow"²³, but that's gone – it went away. A lot of things went away. Then he was discharged at the end of November and went to a day hospital for around fourteen days into December, and then I was talking to them (the staff at the hospital), asking if he could get into Montebello. "No, that's totally hopeless. It's very difficult getting down there". Then I asked, "Can you apply?", "Yes, if you have to be so difficult, then we will." Then after fourteen days, we could go. Then we went for three weeks, and, at that time, I could come as a helper, and when Mr. Nielsen left the hospital, he could walk with a cane and then someone had to walk beside him, and when we came to Montebello, they made him walk by himself with a cane, and he has done so ever since. It just goes to show that intensive training gives such a result half a year later. Just think what would have happened if had it been intensive from the beginning...you know that...there are numerous research studies that show that if you are pulled up by the arm and get a quick rehabilitation then...maybe you're not capable of running a marathon, and you will probably always have to walk with a cane...but a lot can happen, and you know that, but it's not prioritized, because it's old people. I can see that when we apply for money (for the stroke foundation). If I can integrate something into the application about how it might help young people as well, then it helps. It's a strange society. It's slightly bitter because young people also get old. That's how the youth is – we would probably have thought the same. You forget that you get old one day.

As Mrs. Nielsen tells the story of Mr. Nielsen's stroke, the narrative becomes about a struggle to get help. She alludes to the fact that, if it had not been for her own persistent behavior, Mr. Nielsen would have had little to no help in regaining some of his physical abilities. Telling the story, Mrs. Nielsen exploits the narrative to portray an overall

²³ In Danish, it is the expression "Tak skal du have".

ideological point – namely, that youths are indifferent to old people who experience illness – and this is reflected in how the healthcare system in general cares for elderly people. To that extent, the end of her narration points back to mimesis 1, which in the process becomes a shared narration: a narration that suggests that Mrs. Nielsen, by way of experience, knows that there is something wrong with the presumably shared narration of mimesis 1. In mimesis 1, the narrator was not aware of the inherent structural problems of mimesis 3, which in turn restructures the entire narrative past as a past in which they were blind to the *real* circumstances. The way in which Mrs. Nielsen operates in time is particularly curious here; she argues that she, due to having been young once, can understand the attitude and premises of mimesis 1. In this way, Mrs. Nielsen uses her former self as a universal character of “youth”, who – due to her experience and a new categorization in life – is able to see how elderly stroke patients are somehow forgotten and written off by the Danish healthcare system. Mr. Nielsen’s categorization as “old” within the narrative supports the general view that he is not eligible for further treatment in the form of training. Nevertheless, this categorization seems to contradict another categorization earlier in the interview, where Mrs. Nielsen describes Mr. Nielsen’s categorization in the healthcare system as “young”:

(MA) *How long were you admitted, Mr. Nielsen?*

(Mr. Nielsen) It’s a long story because I was moved from there and over to Bispebjerg Hospital, because Mrs. Nielsen knew that out there, they had some proper facilities...

(Mrs. Nielsen) (*interrupts*)...they had a real stroke department. Back then, there weren’t so many of them. Then a neurologist came by and said they would take him because he was so young. They wouldn’t have told me that today, now that I am the chairman of the local stroke foundation. Then I would have said: “What did you say?”

(MA) *That’s an interesting explanation.*

(Mrs. Nielsen) But that was the explanation – that he was young. I didn’t think he was young...he was 60, but yes, he was young. But then they said “yes” and a bed was just supposed to come, so we moved out there on the 19th of May. Otherwise, he just lay and withered away at Amager Hospital with a physiotherapist coming by once a week...maybe twice.

The co-existence of these two perspectives of Mr. Nielsen, who is framed as both old and as young by the healthcare system, may seem contradictory. However, they show how Mr. Nielsen is categorized as “old” due to the nature of his disease, even though his

chronological age indicates otherwise. He is 60 years of age at the time of the stroke, which situates him in a kind of limbo, as the two narratives illustrate. Navigating through a healthcare system that does not definitively place Mr. Nielsen within a certain category confuses Mrs. Nielsen, and makes it difficult to figure out what Mr. Nielsen is entitled to and not. When Mr. Nielsen is framed as “young” in this system, he is entitled to certain benefits; but the same applies to him being framed as “old”, as exemplified by the extent to which Mr. Nielsen will receive free training to regain certain physical abilities. This limbo, being neither one nor the other in the system, represents an overall narrative on the disrupture of identity following a stroke quite well. Mrs. and Mr. Nielsen were searching for an identity for Mr. Nielsen within a healthcare system in which Mr. Nielsen was no longer a healthy man of 60 years of age, but a diseased and crippled man of 60 years of age. Even so, this uncertainty of categorization and identity also has some advantages that the couple has been able to utilize; i.e., negotiating a certain categorization and identity in different situations. For all intents and purposes, from the point of view of the healthcare system, it has been a question of finding out whether Mr. Nielsen was “worth the gamble”. So when the narrative highlights the multiple identities given to Mr. Nielsen, it is consistent in showing how the disrupture had an effect not just on him, but also on the management of his identity and categorization within the healthcare system.

There are numerous examples of contradictory statements in narratives. Sometimes, the dates are mixed up while, at other times, an event previously interpreted one way may be given an alternate interpretation within another narrative. The event may thus be configured in multiple and often contradictory ways that make sense within the specific narrative. The question one could thus ask in reference to Ricoeur’s approach is how self-identity is thus formed if the event is constantly alterable depending on the narrative. From a Ricoeurian point of view, such a criticism about the existence of contradictory narratives could be answered by referring to how a narrative is revoked and altered every time it is told. Sometimes, an event in the narrative may signify one thing and, at another, it may signify something completely different. A certain event might be the plot of one narrative and a minor feature in another. In essence, although the event might be the same, it is configured differently depending on the narrative and the plot of the narrative. To that extent, if the event is multiple, one could question its inherent nature: how can a

multiplicity represent the uniqueness of one's perception of an event? The question almost answers itself: a perception is alterable both in and with time, and thus necessarily represents a multiplicity of configurations. In that sense, and as something that constructs our self-identity, a narration is constantly open for changes and may co-exist along with other narratives; they all may contradict each other in terms of their representation of a certain event. This is best understood if one thinks about how a certain person who one knows well may be configured in various narrations as defined by a range of different adjectives; e.g., good, bad, ugly, etc. While any given narration presents a part of the person in reference to the plot, the person might be different in another narration. Of course, we all know that people have different capabilities of being in certain ways, but in the narration, there is little structural difference between people or objects or even events as they pertain to the plot of the narration. However, in my informants' narrations, particular events are almost always configured in a certain manner; namely, that the stroke is a seminal event – an event that is thoroughly reviewed and disseminated as something that subsequently altered a particular way of life and, in many cases, a communal way of life.

The Narrative as Communal

There is a famous variation of a quote by Søren Kierkegaard that says, “Life can only be understood backwards; but it must be lived forwards” (Thielst 1996). This illustrates the presumption that life is normally lived in relation to history. This history may sometimes become our kernel of identity, and either it is something we strive to learn and use to better ourselves, or it may be what we desperately endeavor to hold onto throughout life. No matter what, our history is thought to have an effect on us; an effect we may not always be able to control in the present. We may become ill as the result of events that took place many years ago, or continue to experience the effects of an old trauma in the present day. In other words, our history follows us, and *life-course analysis* represents an approach to understanding this history. In this chapter, I explore the narrative as a communal construction. I do this by positioning my analysis as an alternative to traditional life-course analysis and by presenting a psychoanalytical, lacanian approach to narrative theory, which emphasizes the importance of a symbolic identity in the construction of a narrative.

Life-course analysis is a multifaceted approach, but as psychologist Dan P. McAdams outlines (McAdams 2005), it consists of three main approaches that have all been significant in the development of this form of analysis. The first approach McAdams associates with the life course is life-span theory, which was primarily developed by developmental psychologist Erik H. Erikson in the 1950s, with great influence from the developmental stages of Sigmund Freud (Erikson 1980 [1959]; Freud 2011 [1905]). Focusing on the epigenetic aspects of the life course, Erikson claims that a human personality evolves through set stages that are buttressed by society (Jensen 1993, 114), and not confronting the challenges of each stage could cause problems in the future. Thus, the theory could be used to explain why an individual might experience feeling as though something is missing in his/her present life. A second life-course approach McAdams characterizes is the idea that the life course does not follow a fixed trajectory, but rather changes according to societal events and is thereby difficult to determine beforehand; this is what sociologist Dale Dannefer (and others) proposes (Dannefer 1984). The third approach McAdams outlines is based on the idea that human personality has a great impact on determining life course, and this personality will not radically change vis-à-vis

societal developments; a description that psychologists like Robert R. McCrae and Brent W. Roberts also propose (MacCrae and Costa 2003) (Roberts and Pomerantz 2004). However, this chapter focuses on a fourth approach to life-course analysis as explicated by McAdams: he argues that, whereas the three other approaches might be relevant to overall life-course perspectives, they do not adequately account for the subjective meanings of people's lives. As a way to address this oversight, McAdams proposes *the narrative approach* (McAdams 2005, 238):

People construe their own lives as evolving stories that aim to reconstruct the past and imagine the future in meaningful and coherent ways. (ibid.)

Taking my vantage point in this excerpt, I introduce some further perspectives to studying the life course with a narrative approach. With such an approach, history is not just history but rather an attempt to make sense of one's own self. Thus, history does not present something "objectively true", as some would claim – for instance, the way that longitudinal studies feature specific measurements – instead, the narration itself tells us much about the present. By giving examples from my fieldwork combined with certain concepts from psychoanalysis, I wish to contribute to the narrative approach by showing how some events may become more significant and determining than others in the construction of a communal narrative.

Mr. and Mrs. Olson live in a small apartment in the Amager area of Copenhagen. They are both around the age of 80. When I meet them, it is less than a year before that Mr. Olson was struck by a stroke, followed by a week of hospitalization. Mr. Olson seems nervous, and Mrs. Olson explains to me that, ever since the stroke, he has had a hard time finding the right words. Consequently, Mr. Olson says very little during the interview, and when he does, he asks his wife if what he is saying is true. The following is an excerpt from the interview:

(MA) *What can you remember, Mr. Olson, from when it happened?*

(Mr. Olson) Not much other than we were having dinner here, weren't we?

(Mrs. Olson) No, we hadn't started eating yet.

(Mr. Olson) But we were about to, weren't we?

(Mrs. Olson) Yes, we were about to, and you hadn't had your glass of red wine, like we usually have, and then I knew something was wrong. Otherwise, I can't really say what we experienced, and you can't remember it. You can remember lying in the recovery room. Do you remember that?

(Mr. Olson) Yes, kind of – don't I?

(Mrs. Olson) You do remember us laughing about me calling you Olson.

(Mr. Olson) Oh, yes...

(Mrs. Olson) (...) But in everyday life, things are working out fine, except not exactly as I would like it.

(MA) *In what way?*

(Mrs. Olson) It's when you (*looks at Mr. Olson*) can't reme...I have more things to do because you don't do so much.

(Mr. Olson) Yes.

(Mrs. Olson) And then the fact that you can't remember makes me very sad, but we can't change that.

(MA) *But what is it you can't remember, Mr. Olson?*

(Mrs. Olson) I just tried something. We saw one of the women we know, who used to clean at our shop (they used to own a dry-cleaning shop). She said that her father also had one (*a stroke*) and that he can't remember phone numbers anymore. So I asked you (*looks at Mr. Olson*), "What's the number for my mobile, and what's the number for the landline?" But you can remember it...how is it you feel that you can't remember?

(Mr. Olson) That's difficult to say, I think.

In this example, it is interesting to note the construction of the narrative in combination with assumptions about the nature of a stroke. While Mr. Olson is assumed to have a limited memory because of the stroke, he does actually remember the things Mrs. Olson questions a person who has had a stroke would remember (i.e., telephone numbers). What is particularly interesting is how his minor speech deficiency is accentuated as a sign of memory loss. In other words, Mr. Olson is presented as being incapable of constructing his own narrative – and thus his own identity – due to the stroke, and instead his wife becomes the constructor. However, she seems to construct a narrative that is influenced by

what she thinks a person struck by a stroke would be like, and how this person would narrate his life.

In relation to life course, it is crucial that the narrative changes *as a result* of the assumption that Mr. Olson is incapable of remembering his own narrative. Thus, we find the exact opposite of what sociologist Anthony Giddens is quoted saying in the McAdams article: “A person’s identity is not to be found in behavior, nor – important though this is – in the reactions of others, but in the capacity to keep a particular narrative going” (McAdams 2005, 241). Noticing the hesitant way that Mr. Olson talks about what happened – i.e., by answering my questions by posing questions to his wife – shows how doubtful he is about his own narrative. One could argue that this uncertainty is due to the relatively unique situation Mr. Olson finds himself in, but one could also say that it is difficult for him to reclaim a narrative that has been taken over by his wife. Finally, we could add that Mr. Olson might appreciate Mrs. Olson’s possession of the narrative, as it offers a kind of safety in terms of his unique identity; i.e., that there is someone who knows the narrative better than he does, thus confirming the existence of that particular narrative.

In my interview with Mr. and Mrs. Jensen, we see another example of how a communal narrative is constructed. Between 1990 and 1997, Mr. Jensen had a total of seven strokes – approximately one each year – with the last stroke being, as he expressed it, the one that “broke the camel’s back”. During a conversation about traveling, Mr. and Mrs. Jensen construct a very illuminating narrative about a journey to the North Pole:

(Mrs. Jensen) ...but you’ve felt like traveling before, and we’ve also been out traveling. We’ve been to the US twice, and we visited some friends at the Ministry of Foreign Affairs in Brussels, but when you had just been discharged from the hospital, we went abroad, and Mr. Jensen walked a lot better then than he does now, and tell us, Mr. Jensen, where we went...

(Mr. Jensen) First, we were at the North Pole.

(Mrs. Jensen) (*explains about their friends at the North Pole*) ...then Mr. Jensen became ill, but we did it, anyway – didn’t we, Mr. Jensen?

(Mr. Jensen) Yes, and I don’t regret it.

(Mrs. Jensen) (*directed at Mr. Jensen*): Tell him how we did it...how we got up there.

Mr. Jensen tells the story and, as in the excerpt above, his wife supports him whenever he misses a detail she finds important. What is so interesting about this is the seemingly rehearsed aspect of the narrative²⁴. They both know how to tell the story, and it becomes Mrs. Jensen's way to assess Mr. Jensen's mental state; i.e., as a way of asking: "Is Mr. Jensen still capable of telling the narrative that we both know?" Thus, the narrative – and the way the narrative is told as agreed to by both parties – is crucial in assessing both Mr. Jensen's health as well as his identity (e.g., does he have some degree of dementia, etc.). At the same time, it also becomes a way to assess their relationship.

Returning to the Olson interview, the stroke occupied a specific space in their communal narration as something that changed the couple's particular way of being. This became clear when Mr. and Mrs. Olson each explained how they thought their everyday lives had changed after the stroke. One of the things Mrs. Olson noted was how her husband was no longer able to take their usual walk around the neighborhood. Attributing this to his stroke, I asked at the beginning of the interview when his inability to walk this distance had started; she answered that Mr. Olson had not been able to manage it for over two years. Realizing that this did not correspond with the timeframe of his stroke, she blamed general ageing instead. This demonstrates how Mr. Olson's categorization as a stroke victim initially serves to explain the change in their everyday lives, while general ageing is then given as the explanation. In this sense, it is important that the stroke is used as explanation in the narrative; i.e., to assign meaning to a change. This is something one often encounters in interviews, where the stroke – being a seminal event – is used to explain changes, most of which are often for the worst. However, the stroke is not only an event: in many cases, it also becomes a point of identification. Thus, being a stroke victim is also potentially an identity that may give meaning to everyday life and explain a variety of limitations.

As seen in these two examples, the construction of a narrative can be communal. However, it is communal in another way than simply being a negotiation between each of the couples. Mrs. Olson is in charge of Mr. Olson's narrative due to his uncertainty; he continually seeks his wife's help to re-narrate their set narrative. However, his wife reveals

²⁴ This will be further explored and substantiated in the chapter "This Other Brain of Mine"

her own insecurity about the narrative when she realizes that the stroke cannot explain a change in their everyday lives (e.g., being unable to take their daily walk). In contrast, Mrs. Jensen knows their communal narrative and can correct Mr. Jensen if he makes a mistake when telling the story. Mr. and Mrs. Jensen seem to have constructed a narrative upon which they have both agreed; but Mrs. Jensen uses it to test Mr. Jensen's mental abilities, and the narrative thus gives meaning insofar as Mr. Jensen is able to tell it.

According to McAdams, a person uses narratives to provide meaning to events in life; however, by incorporating fieldwork examples into this chapter, I illustrate how another person may provide meaning. In effect, meaning can be provided by the narrative another person tells, and this person may seek assistance in giving meaning to the narrative through a range of ideas about what happened when, for instance, a stroke occurred. The question that remains is how to make sense of the construction of such communal narratives. To do so, I believe it would be productive to bring in the psychoanalytical concept of the *symbolic mandate*.

The Letter that Always Arrives at Its Destination!

One of the most essential tenets of psychoanalysis is that a subject is always expected to occupy a particular space in a symbolic order. Originating from Claude Lévi-Strauss's *Les structures élémentaires de la parenté* (Levi-Strauss 2002 [1948]), the symbolic order refers to the realm of language, signs and the law. The space that a subject is expected to occupy is one of symbolic identity, which can be anything from being a father, being 40 years old, a lumberjack or all of these things simultaneously; however, the separate parts must all share a *universal particular* identity. As such, a universal particular is that which remains as the universal in the multitude of its interpretations, ultimately characterized by its failure (Žižek 2008, xii). In that sense, a subject is born into a symbolic order, that provides the subject with its symbolic identity/mandate; i.e., before a child learns to speak, it is named, gendered, placed within a social framework and referred to as having a specific personality that relates to its placement within the symbolic order (Lacan 1999 [1966]). However, one might not fulfill one's mandate as a father, as a particular age, as a lumberjack etc., and it is exactly this failure that constitutes true universality. What is important to understand is that the symbolic mandate is inherently empty – the symbolic mandate is the failure of

universality. In this sense, one is always a singular standing in for the universality. As Louis Althusser illustrated with the term *interpellation*, a subject will (mis-)recognize itself as the addressee of ideological interpellation and, as such, a symbolic mandate becomes a signifier, facilitating the interpellation of the subject (Althusser 1972, 174). Slavoj Žižek further explains how this process occurs:

This illusion (that one is the missing part of the symbolic network) is produced by a kind of “short circuit” between a place in the symbolic network and the contingent element which occupies it: whosoever finds himself at this place is the addressee since the addressee is not defined by his positive qualities but by the very contingent fact of finding himself at this place. (Žižek 2008, 13)

In other words, by means of (mis)recognition, the symbolic network forces categorizations onto the subject. As Žižek explains, this is “why a letter always arrives at its destination”:

When I recognize myself as the addressee of the call of the ideological big Other²⁵ (Nation, Democracy, Party, God, and so forth), when this call “arrives at its destination” in me, I automatically misrecognize that it is this very act of recognition which *makes* me what I have recognized myself as – I don’t recognize myself in it because I’m its addressee, I become its addressee the moment I recognize myself in it. *This* is the reason why a letter always reaches its addressee: because one becomes its addressee when one is reached. (ibid.: 14)

Recognizing oneself as the addressee is thus to occupy the empty space in the symbolic network. However, this does not mean that the subject’s ideas of his/her own particularism in the symbolic network are dismissed by occupying a seemingly universal specific position in this network. Rather, it means that this particular position is inverted in its true form by being tied to the nature of the *mis*recognition inherent in the lacanian version of interpellation (Žižek 2006, 131). In other words, an imaginary notion of unique subjectivity prevents the full recognition of oneself from being reduced to the symbolic position, while it simultaneously supports this categorization. Thus, a person can accept being called “old” while not accepting the universalism inherent in this label.

²⁵ There is often something/someone who calls for an addressee to occupy a symbolic mandate. This is the so-called “big Other” within psychoanalysis. As I expand on the concept of the Other later in the chapter “This Other Brain of Mine”, I do not venture too far into a description of the big Other here, but suffice it to say that the big Other is an Other that appears to support the categorization of the symbolic mandate by promising a foundation that sustains the symbolic mandate. In that sense, the big Other facilitates the gap in the symbolic mandate that allows the subject enough space to fulfill the symbolic mandate.

Based on the aforementioned brief theoretical outline of certain principles within psychoanalysis, I would like to approach the communal narrative by looking at how an incorporation of the symbolic mandate into the analysis might provide insight into the creation of a life-course narrative, especially if the narrative is communally constructed.

Returning to Mr. and Mrs. Olson, we see how Mr. Olson, having been struck by a stroke, receives a symbolic mandate – and, even though it is inherently empty, it becomes his narrative identity. This is most clear when we examine the earlier quote regarding Mr. Olson’s memory, in which Mrs. Olson becomes unsure about what Mr. Olson can remember. Searching for good examples, she mentions the experience of an acquaintance who also had a stroke; however, she knows that Mr. Olson does not suffer from the same type of memory loss. More interesting is that neither of them mention any other way that he cannot remember. In other words, the narrative framed by Mrs. Olson becomes structured around a symbolic mandate. Mr. Olson is still essentially Mr. Olson; however, he is reduced to Mr. Olson who had a stroke, and this fact is exactly what changes the narration. From a psychoanalytical viewpoint, he is the epitome of an empty signifier; however, inconsistencies in the narration cause Mrs. Olson to reconsider the narration and thus Mr. Olson’s symbolic identity. Following this logic, one might say that Mrs. Olson transforms/reduces Mr. Olson to a particular position in the symbolic network, which then determines his narrative identity. However, this symbolic mandate does not serve to provide meaning to Mr. Olson’s current state of being. Thus, the narrative is influenced by Mr. Olson’s lack of compliance with the symbolic mandate.

Psychoanalysis thus elucidates how a traumatic event may change the primary symbolic mandate, and thereby also the narrative identity. In this case, the event is Mr. Olson’s stroke, which initiated a radical change and is used to provide meaning for the changes in the couple’s everyday life: Mr. Olson not being able to walk the same distance is a very illustrative example of this. From this perspective, the stroke as an event assumes a greater narrative importance than others, because Mrs. Olson uses it to construct Mr. Olson’s symbolic identity. Rather than being an event that is equivalent to others in a narrative, it becomes a seminal event due to its transformation of Mr. Olson’s symbolic identity. At this point in time, one could argue that, in terms of what the symbolic identity means, the

Olsons are confused, as Mr. Olson bears no visible marks of this identity; e.g., paralysis, memory loss, etc. Everything they have heard about stroke victims does not seem to correlate with Mr. Olson's actual experiences, but it is forced upon him as his way of being. We could say that his wife recognizes him as the addressee of the call and, in that instant, he is transformed and so is their communal narrative.

When looking at the Jensen couple, Mr. Jensen is also given a symbolic identity that, by consciously fulfilling it, he may also be acknowledged as being more than it. Through their narrative about the North Pole, Mrs. Jensen assesses his symbolic identity, and the successful narration suggests that Mr. Jensen is something more than his symbolic identity. If he does fully become this symbolic identity, he will not want to live anymore: Mr. Jensen makes this quite clear during the interview, saying that he does not want to be a vegetable and that, if he has another stroke, his wife has promised not to call an ambulance immediately. Something that Mrs. Jensen knows will be extremely hard not to do. The multiple strokes – and the last one, in particular – have solidly placed him with a symbolic identity that he cannot escape, and it is through the communal narrative that he confirms that he is more than this symbolic identity. While the communal narrative thus confirms Mr. Jensen as something more than his symbolic identity, the symbolic identity is also essential in constructing the communal narrative. In essence, one could argue that Mr. Jensen's symbolic identity is an important part of the couple's narrative, and this symbolic identity has been secured by his strokes.

In both the examples of the Olson couple as well as the Jensen couple, the stroke is the seminal event through which the narrative is constructed. It is a way of conforming the narrative to fit with a symbolic identity that, although it is inherently empty, is stuffed with individual connotations and semi-certain definitions. Meaning, as explored in the chapter "The Narratives of Everyday Life", is thus proposed in this chapter to be constructed in relation to the change of symbolic mandate. In the narrative, it is also the possible construction of a future horizon; of disposing the symbolic identity or completely succumbing to it. This is how a narrative approach, coupled with a psychoanalytical approach to the life course, may not only tell us something about the past or the present, but also about the future.

Rather than evaluating a narrative approach to life-course theory, I have attempted to contribute perspectives to the approach by including examples from my fieldwork that illustrate how a narrative is often a communal construction. By combining my fieldwork insights with concepts from psychoanalysis – especially the theoretical concept of the symbolic mandate – I have illustrated how the construction of a narrative may be communal, and how a communal narrative may be constructed in relation to a specific symbolic mandate. In addition, I have shown how a seminal event such as a stroke may provide a new meaning to a narrative and thus prompt changes in everyday life. In conclusion one might add to the initial quote by Peter Thielst on Kierkegaard that to live life forward and to understand it backwards, according to Kierkegaard, means that it is actually not possible to understand temporal life as it does not rest and allow us to take a position (Thielst 1996).

The Regimes of Hope

(Mrs. Nielsen)...we weren't supposed to be here.

As mentioned several times throughout the thesis, the lives of my informants have been disrupted by stroke. In some cases, the disruption has been minor, and in others, it has been a completely life-changing event. Again, my fieldwork indicates that the physical impact of a stroke is not necessarily the most significant factor in relation to experiencing the stroke as a disruption. Rather, the factor that seems to be of the greatest importance is how the disruption is *experienced* as being *disruptive*. In the earlier chapters on the narrative of the stroke, I attempted to pave the way for understanding how relativism is inherent in presenting the disruption as experienced, and I have shown how a disruption is related to the temporal dimensions of past, present and future. In this chapter, I examine the concepts of hope and disappointment in relation to disruption. I argue that, whereas hope and positive thinking in general are conceptually put forth as ideas that may ensure a way to move beyond the disruption, they may also be experienced as a regime that entails specific behavior. In that sense, what I call “the regimes of hope” may be considered as alienating forces that instead prompt disappointment.

In *Smile or Die – How positive thinking ruined America* (Ehrenreich 2009), journalist and author Barbara Ehrenreich attempts to illustrate how an immense focus on being positive in the face of crisis has become an inherent feature of American society. She tries to show how this is in response to an earlier Calvinist way of coping with life, as described by Max Weber in *The Protestant Ethic and the Spirit of Capitalism* (Weber 2002 [1905]), and how this paradigm change has been instituted at all levels of society. Ehrenreich describes the cult of positive thinking as being somewhat similar to what is found in Aldous Huxley's *Brave New World* (Huxley 1932) with people partaking in events that promote positive thinking – events particularly directed towards self-proclaimed life coaches and business-people. What Ehrenreich points to, however, is not just the type of capital associated with being positive; more interestingly, she presents the narrative of how being positive will change one's life for the better, even in cases of immense crisis. Based on Ehrenreich's own experiences with psychological therapy in relation to her struggle with breast cancer, her

work portrays how difficult it is to vent one's frustrations, and also how not being positive may provide a rationale for why one did not overcome the disease. In this respect, being positive becomes an imperative of illness management, and the myths of scientific results that support this argument are numerous, deriving not only from psychology but also from general medical science and nuclear physics.

The Tyranny of Positive Thinking

The issue that Ehrenreich raises is what I call 'the tyranny of positive thinking'²⁶. In a similar vein, many of my informants struggle with what they experience as a pressure of having to fight and stay positive. Mrs. and Mr. Nielsen provide a good example of this issue:

(Mrs. Nielsen) ...it's to illustrate how much it changes a person to have a stroke. Of course, some people get around it more easily, and that's probably got something to do with how young you are...the younger, the better. But there will always be remnants of something, and you can also feel and hear it in a singer like Sanne Salomonsen²⁷ – you don't doubt it for a second. The whole charade about a comeback – yes, yes, but she's not worth listening to. That's just how it is. That's where Mr. Nielsen and I can get furious (when people say), "It's just about fighting, because if you fight then you can get really far" and phrases like "I'm happy about my disease...that I got the stroke because now I have another"...you know..."that it's been a really positive experience". If we go to an unfamiliar place and hear someone say that, we leave. We've done that a couple of times at different folk high schools²⁸ when we've attended courses where they (the high school) had some idea about bringing in a person to say something like that, and they're told that it's a freaking lie. We can't understand how people can even think of saying that.

There are several positive narratives about stroke survival; general stories about how the stroke changed a life with a hectic career into a more reflective and balanced life, stories about how to regain one's old lifestyle, the story of a neurologist who had a stroke that provided her with new insights into understanding the brain in *My Stroke of Insight* (Taylor 2006) and a movie, *Flawless*, about how a stroke may force one to overcome prejudice (Schumacher 1999) – just to mention a few. Depicted in the media as a tragic event that may be mitigated if one "just" listens to what the stroke (as an anamorphous being) "is

²⁶ Although the use of the word "tyranny" may seem slightly strong, it is meant to imply the forced choice inherent to living in a regime. To that extent, the metaphor of "the regime" relates to the simultaneously authoritarian and paternalistic ambition of regimes.

²⁷ Sanne Salomonsen is a Danish pop-rock icon in her late 50s who had a stroke in 2006.

²⁸ The Danish term is *højskole*.

telling you” – to change your lifestyle, reconsider your relationship to your family, work, etc.

From the interview excerpt with Mr. and Mrs. Nielsen, we see how frustrated they are – not only with the experience of Mr. Nielsen’s stroke, but also with other people who have had a stroke and who insist that their own experience of stroke was *not* an experience of deficit but rather a gift. To Mrs. Nielsen, it makes no sense to view the stroke as a “gift” and, after having dealt with the repercussions of Mr. Nielsen’s stroke for a number of years, Mrs. Nielsen is quite convinced that the stroke is not something that one can fight to get rid of – especially not with positive thinking. The argument that one can conquer a stroke influences Mr. and Mrs. Nielsen’s narrative, as it somehow becomes a moral indication of how they have not fought hard enough. Further, it has the potential to create a rift between Mr. and Mrs. Nielsen – with Mr. Nielsen being blamed for not fighting hard enough, and thus guilty of purposefully making Mrs. Nielsen’s life as difficult as it is now. It is precisely this moral aspect of fighting that seems to be a huge problem for a number of my informants.

Essentially, the idea of fighting, or staying positive, is directed at creating hope. In the case of the Nielsens, however, it seems to have the opposite effect: it becomes an indication of how their moral flaws put them beyond the reach of hope. Here, hope is presented as the hope of getting better, or getting wiser, thus adding to their disappointment with life. However, the couple’s narrative is far from a narrative of surrender – rather, as they present it, it has been a constant struggle: with the implications of Mr. Nielsen’s stroke, including his immense fatigue and partial paralysis; with the fight for their rights; and finally, with the regime of hope. Although the couple has done their best to navigate within the municipal system, in terms of securing rights and benefits for Mr. Nielsen, the “maintenance training” that Mr. Nielsen is now receiving from the municipality does not really correspond with a narrative of recovery and further insight. Furthermore, Mrs. Nielsen mentions how they will be forced to leave their house soon, as her pension funds are nearly depleted. On top of that, she is not sure whether they will be able to keep their car, which, due to Mr. Nielsen’s partial paralysis, is the only way they can get around. During the interview, the couple also complain about the loss of their vacation at a center

for the handicapped; the center was supported by the Danish state, but has now lost a large amount of its funding, forcing it to stop offering the vacations:

(Mrs. Nielsen) So we went there last year, and it was simply a great two weeks of holiday. It's also a place Mr. Nielsen knows because we have been to courses and such there with 'Hjernesagen', so Mr. Nielsen feels at home over there; he knows where everything is. We also signed up for it again this year, and we were told that she (the officer in charge of the funding) couldn't see any reason why we wouldn't be eligible to go there again this year. So, we received a letter two weeks ago, one for each of us, and I thought 'Now the confirmation has arrived', but then it bloody well said that the Department of Social Security had decided to change the rules for support to the assistants of the handicapped, so it wasn't possible. So they have canceled all four holidays. We have to bring that government down, because the handicapped sure as hell don't need it....

(MA) *That's odd...that there's been nothing in the media about that.*

(Mrs. Nielsen) It is, but it gets drowned out, because it's not the only place where there are cutbacks in terms of the handicapped. There are cutbacks on everything and everyone. The ones who aren't productive, 'Let's see what we can do with them'.

(Mr. Nielsen) Every time they say reforms, it means cutbacks.

(Mrs. Nielsen) But it's tough. When the letter came, I thought, 'No, Mr. Nielsen is going to be so unhappy when I tell him about it', and he really was unhappy because we had been looking forward to [the vacation]. And we can't just say, 'Well, then we'll go somewhere else'. Then my daughter-in-law said, 'Can't you go to Tisvildeleje²⁹?', and I said, 'Hello, that's around 9,000 kroner for a weekend'. There aren't any places we can go. Maybe they think, 'Now that you're 71 and 75, you don't need a holiday, and you live in a house and have a garden', and that's true...that we are better off than so many others, but that doesn't change anything. (...) Mr. Nielsen was really sad, and then I said, 'You know what, Mr. Nielsen, try to think about the people we were with last year – they're not going on a vacation, either'.

(Mr. Nielsen) Yes, many of them can't walk or stand, eat or anything. They can only sit.

As Mr. and Mrs. Nielsen make clear, losing their vacation is a major disappointment to them. Talking about it at great length during the interview, the vacation becomes a space in time that is in complete opposition to their everyday life. Being left only with their everyday life – which Mrs. Nielsen describes and experiences as being increasingly difficult – does not leave them with much to look forward to or to be positive about. After abandoning the narrative of “hoping for progress”, pleasures such as a vacation are

²⁹ An area north of Copenhagen widely known for its numerous summerhouses, guesthouses and hotels.

brought to the foreground as something concrete that literally makes their everyday life tolerable. However, one might also argue that the narrative surrounding the loss of the vacation is something that the couple agrees on, and which channels their annoyance with the current state of affairs into something specific. During the interview, it is one of the only instances where the couple recognizes how they can have a great time together. Otherwise, when they speak about happy times, these are expressed as only being in the past – before the stroke. In this way, the vacation also assumes the role of something lost, which has the double function of affirming the existence of good times. In this narrative, there is no hope whatsoever, even though changing the government is repeatedly suggested as a solution to regaining their vacation, while they reject any ideas for alternative types of vacation. In this way, their hope laid in the vacation once offered. This very much relates to what seems to be the only hope for the Niensens – to not lose any more of what they have already lost and are currently losing. For Mr. and Mrs. Nielsen, the hope that they hold on to the most is the hope of being able to continue their cyclical way of life, even though they are not very satisfied with it. But this way of life is slowly being pulled apart by the stroke's subsequent disruptions – Mrs. Nielsen's bad back, depleting their pension funds, losing their house, having to sell their car, etc. Their best hope is to maintain the status quo – not for Mr. Nielsen to recover, but for them to be able to live a life without losing anything further because of a disruption that occurred so many years ago.

In anthropological literature, a disruption and its related illness management are often referred to as a liminal period (Murphy 1987). In *Disrupted Lives*, Becker writes:

The stories in this book all have a beginning, a middle, and an end, although in many cases the imagined and hoped-for end is not yet in sight. (Becker 1997, 28)

However, this is not the case with the Niensens, whose hoped-for end is more similar to a continuation of their current life. In their case, it is not something one transcends; instead, it is something one copes with. For them, the disruption does not entail any kind of progress; rather, it created a life that, as Mrs. Nielsen so eloquently stated at the beginning of this chapter, they were not supposed to be living. With both Mr. and Mrs. Nielsen experiencing a deterioration in health and depletion of finances, the present is as good as it is going to get. So we must ask: is Mr. and Mrs. Nielsen's hope really situated in the future

– is the future hope what sustains their being? Their hope is not a hope of progress; it is a hope of no further change. A hope that the disruption ends its continuous hold on them, and that they will be allowed to live as they have lived for the last couple of years, even though these years have not been particularly kind to them. However, if we insist on hope as an essential remedy in the management of an everyday life with illness, I would argue that the hope that is qualitatively similar to what is “offered” by the regime of hope is that hope that is related to Mr. and Mrs. Nielsen’s imagination of how things could have turned out differently. This hope, being retrospective, does not focus on progress, but gives the disruption a character of “teleological coincidence”. With this term, I mean to imply the simultaneous and contradictory movement between the disruption as what had to happen – the informants are in a certain situation – and as what happened due to unfortunate circumstances. For the Niensens, this means that hope lies in the disruption as something that prevents them from achieving “the good life”. As much as the disruption is a problem in the present and the future, it also conceals the possibility of life as it could/could not have been. Turning to psychoanalysis, the disruption becomes a locus of enjoyment, of something hidden in life – unable to come out. As Žižek writes in *Enjoy Your Symptom* (Žižek 2008), enjoyment (as *jouissance*) is the pleasure in pain; as such, it is inscribed in the search for the fulfillment of enjoyment – in psychoanalysis, what is called *objet a*:

The *objet a* prevents the circle of pleasure from closing, it introduces an irreducible displeasure, but the psychic apparatus finds a sort of perverse pleasure *in this displeasure* itself, in the never-ending, repeated circulation around the unattainable, always missed object. (...) *objet a* effectively functions as a rift in the closed circle of the psychic apparatus governed by the ‘pleasure principle,’ a rift which ‘derails’ it and forces it to ‘cast a look on the world’, to take into account reality (Žižek 2008, 56)

My argument is that the disruption may be seen as a *big Other* – something that promises a way to find the *objet a* – and thus resolve the rift in the circle³⁰. Yet while the disruption ensures the existence of enjoyment, it also makes it impossible to ever approach it. In this way, the disruption as a big Other facilitates a point in the narrative where one was on track to resolve the rift, but the disruption stopped this en route. With the Niensens, such a claim is most obviously supported by the way in which the narrative about Mr. Nielsen’s stroke event is told – it emphasizes the tragic circumstances of the stroke, which happened

³⁰ See the forthcoming chapter “This Other Brain of Mine” for a more detailed description of the big Other.

mere days after Mr. Nielsen retired and just when they were about to enjoy life. In a paradoxical inversion, when talking about the idea of *hope* in this case, hope is the loss of hope. To that extent, and as seen from a psychoanalytical perspective, hope derives its meaning from the impossibility to attain hope. Although hope is traditionally related to an event in the future, my analysis here proposes that a retrospective hope exists; a hope that allows for the impossibility of a hope for progress and meaning.

Willful Perspectives

Mrs. Poulsen had two transient ischemic attacks in the summer of 2012. When I call her to ask for an interview, she explains that she has overcome her overwhelming sense of fatigue, and that her everyday life is now back to normal. She is still interested in doing an interview so, in January 2013, I visit her at the non-detached townhouse where she lives with her husband in Outer Copenhagen.

Mrs. Poulsen is 66 years of age, a retired secretary who has always enjoyed doing sports, especially playing Ping-Pong. Despite two slipped discs sustained a few years before her stroke and five operations for her slipped discs, she has kept playing Ping-Pong as well as exercising on a regular basis. However, since her stroke, things have changed.

Mrs. Poulsen has experienced a great deal of adversity in many areas of her life, but – as she points out during the interview – she has always overcome hardships through stubbornness and willfulness. Similarly, she explains that getting past the consequences of her stroke, such as the fatigue, is partially due to her strong will. She exemplifies the force of her volition during a story about when she quit smoking:

(Mrs. Poulsen) How many years ago did I stop smoking... it's 16 or 17 years ago now, and it was my will that made me do it. If you only knew how many people I know who simply can't stop. I'm stubborn, and I think that's a good thing. You have to get on with it and so on. I don't put myself in a corner and twiddle my thumbs, but if you're too tired, then it's obvious that you can't...you don't feel up to it...but then it'll come to you.

Mrs. Poulsen clearly feels that she has moved beyond the repercussions of her stroke, often talking about her fatigue in the past tense. She has gotten through the liminal phase and can look back on the experience – reflecting about what she did to get past it. In that

sense, she uses a restitution narrative (Frank 1995), as explored in the chapter “The Narratives of Fatigue”. This is exemplified in the following quote:

(Mrs. Poulsen) It's been a very slow process, but looking back at it now, it's actually gone pretty well. I can still get tired. Generally, I would say that you're more tired than you were before – even though it's going a lot better, you're still getting tired faster, but that might have something to do with your physical fitness not being what it used to be. It sort of bites its own tail. (...) I probably have a little anxiety about it. When you bike...I'll begin by biking 10 to 12 kilometers, you really get your...you're totally wiped out, and the sweat just pours down, and then I might get a little nervous that it might set something in motion, and I don't really know if it would.

The paradox of the above quote lies in the discrepancy between what Mrs. Poulsen thinks one should do to not feel so fatigued after a stroke – namely, exercise – and what she is afraid might happen if she exercises as much and as hard as she wants to. In that sense, the stroke continues to have a disruptive effect; it makes her unsure about her former exercise praxis, and it forces her to accept feeling slightly more fatigued than before her stroke.

Retrospectively, she also doubts whether exercising actually does prevent strokes:

(Mrs. Poulsen) You might say that I have been amazingly lucky, and it's kind of crazy that something like that can happen when you've been exercising so much. You can't really...but it sort of stays with you. It really does – I don't know if one can ever get past it.

Even though Mrs. Poulsen says she has gotten past her stroke, its disruptive character is still inherent in her life, and she is beginning to feel as though she has to reduce her level of activity to prevent another stroke, as well as to limit her activities. Rather than hope that things will get better, she accepts her present condition and the fact that the stroke has forced her to consider balancing her level of activity with her age. Mrs. Poulsen is well aware that she was lucky and, although she emphasizes her willfulness in relation to getting better, she knows that she could have been struck by her stroke in a way that would be a challenge for even the strongest will. Her brother-in-law, who was present when she had her first stroke, has also had a stroke but one that left him partially paralyzed. Because of this, Mrs. Poulsen realizes that she cannot tempt fate, and she avoids doing so by changing something that she did before her stroke – even though her decision to cut down on exercise, from a medical point of view, seems to be somewhat illogical. If Mrs. Poulsen hopes for anything, it is simply that she does not have another stroke.

Mrs. Poulsen is not an opposite of the Nielsens. She does not live according to a regime of hope and, although she emphasizes volition, she has a more nuanced view about how far volition may take someone, depending on the severity of his/her stroke. Thus, Mrs. Poulsen serves to present a perspective on how, even though she has moved past the disruption, it is still present in her actions and choices; it is a constant reminder of what could have happened. A reminder that she could have become partially paralyzed or worse and that, in that sense, her life could have been similar to her brother-in-law's or, for that sake, Mr. Nielsen's. As Mrs. Poulsen frames it, there is little hope in such a life.

With the Nielsens, it seems that the “regime of hope”, as I have presented it in this chapter, is far from supporting the Nielsens in their attempts at managing an everyday life after stroke. In fact, as the Nielsens explain it, the forced notion of hope that they often meet whenever attending different courses or speaking to other well-meaning people is more a location of fatigue than anything else. It points to their “failure” in managing a life after stroke in the best possible way; namely, that of hoping that things will get better, although they know they won't.

In this chapter, I have shown how hope as progress may present itself as a tyrant in a person's everyday life. After a critical illness, the regime surrounding hope created disillusion among my informants and made them feel as though they have a moral flaw. The example of Mrs. Poulsen, who experienced an almost full recovery from her stroke, has allowed me to illustrate how the effect and severity of a stroke has an impact on a person's potential to return to his/her everyday life, and that volition and hope may only bring a person so far.

Locating Pain

(Mrs. Henriksen) ...I know that if I have too many problems, then it affects my head – I get dizzy, feel unwell and nauseous and start experiencing pain; I just feel really bad. Some people might say that all of my symptoms are psychological. That may be, but I have doctor's statements stating that I'm not psychologically unstable. Even though I feel okay, I'm still experiencing pain, I'm just not experiencing as much pain. I try to limit doing the things I know may cause pain. I do that consciously.

This chapter explores pain management among my informants. By using the lens of location I argue here that pain, much like fatigue, is connected to a certain object, act or event. Pain is thus a rhetorical entry into a further study of the locations of fatigue. Employing philosopher Elaine Scarry's definition of pain, I show that, because sensations like pain and fatigue are subjective in nature and thus beyond immediate communicable reach, it is the *location* of pain caused by an object, act or event that is crucial for communicating pain. As much as it may explain their pain, I argue that this location is what gives my informants the opportunity to manage their pain. Through my empirical examples, I illustrate the multiplicity of ways in which pain may be located in objects, acts or events, and how – in addition to providing meaningful communication – this location also plays a significant part in pain management.

A Body in Pain

In her book *The Body in Pain* (Scarry 1985), Elaine Scarry positions pain as the most inexpressible emotion of all. This inexpressibility is due to the fact that pain is impossible to describe to others and is essentially a person's own unsharable experience. Therefore, when two people talk about pain, it may seem to represent two different entities. As Scarry argues:

Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language. (Scarry 1985, 4)

Scarry ultimately argues that we all know what pain is, but we cannot comprehend via language how another person *feels* pain, and it is precisely this unsharability that secures pain its place in the world. Pain is beyond language, as it does not only resist language, but through this resistance, it also negates language (Scarry 1985, 4). In essence, pain

articulates the sounds before language is learned. Furthermore, Scarry argues that pain, as opposed to other sensations, does not have an *of* or a *for*, and thus it does not take an object, which also causes it to resist objectification by language (Scarry 1985, 5). Scarry's definition of pain echoes a central problematic explored by several semioticians (de Saussure 1983 [1916]; Barthes 1988; Peirce 1998 [1868-1902]); namely, whether a person's experiences of reality come before language – i.e., whether one may actually experience “unarticulated” pain. Although this question may seem ridiculous from a positivist realist/naïve realist point of view – or, as Ferdinand de Saussure (1857–1913) saw it, from the point of view of the general public – a public that according to de Saussure would argue that language names things and experiences in the world, and is thus simply a *nomenclature* by which “things are named what they are” in a one-to-one relationship – it puts an emphasis on the issue of representation.

To both de Saussure and his contemporary, semiotician Charles Sanders Pierce (1839–1914), language necessitates the reference to “move beyond the particularity of the individual instance” to be communicative (Chandler 2007, 60). This requires universals and categorizations by which things are grouped; e.g., saying that you saw a tree does not make that specific tree specific, but it does ensure communication. To the person being told about the tree's existence, the tree is first and foremost an abstract concept. This might seem to suggest that concepts or ideas are inherently realized before language, but again, a Saussurean interpretation would emphasize that ideas and concepts are not established prior to linguistic structure (de Saussure 1983 [1916], 114-115), but are rather defined by language. Thus, reality is “created by the media which seem simply to represent it” – in this case, language (Chandler 2007, 61). From this point of view, Scarry's approach seems to resemble psychological phenomenology, operating with the idea that words are the things for which they stand, and that pain transcends this boundary because it is impossible to articulate. However, my fieldwork shows that a linguistic categorization of pain may occur, and that the experience is quite well-articulated in and through the use of language. I also found that both the management and understanding of pain are related to the communicable locations of pain.

Most of my informants describe experiences of pain in one way or another; some of them struggle with severe pain, while others experience it to a lesser degree. Yet it is always expressed as being tied to something specific: an object, an act or an event. As demonstrated in the opening quote of this chapter, Mrs. Henriksen is trying to determine where her pain is located. She attempts to connect it to something particular, but experiences difficulty doing so because she is confused about where her pain *is*. In the terminology she uses, it is either locatable physically or mentally, but since she does not know exactly from which of these two alternatives her pain derives, she approaches it more holistically. This results in her actively avoiding or seeking out certain actions and events to alleviate her pain and, in order to get an idea of the character of her pain, she tries to logically connect these acts and events. To that extent, Mrs. Henriksen ties her pain to these acts and events, even though the inability to locate her pain makes it challenging for her to give others an understandable explanation of why/how she is experiencing pain. In other words, trying to locate her pain makes it difficult for her to communicate it.

If we try to approach pain as communicable and tied to certain events and acts, we need only imagine giving birth and the multitude of different pain sensations that a woman may experience in the process. Giving birth is associated with a specific kind of pain – a pain that is awful to varying degrees, but which, from a societal perspective, is commonly agreed to be worthwhile (if everything goes well). Here, pain becomes an object to be transcended in order to obtain something specific – having a baby – and the experience is recognized in relation to its outcome. With cancer, the tumor and its potential metastasis are seen as the object of disturbance that are causing pain and, in the case of phantom pain (explored in depth by Merleau-Ponty), the arm as an object that was torn off a person's embodied being constitutes pain (Merleau-Ponty 2005 [1945]). I argue here that pain *is* communicable – not by how it is physically felt, but by the location of the object to which it is connected. When pain is not temporary, such as with chronic conditions, or when it is difficult to connect to a specific object, such as with medically unrecognized diagnoses, it presents itself as incommunicable – even though the location of pain in chronic conditions makes up for the difficulty of communication. For example, one formerly unrecognized and still medically-contested diagnosis is fibromyalgia. The partially accepted diagnosis describes fibromyalgia as being related to muscle rheumatism;

but moreover, it constituted and created a more distinct object of pain by means of a physical location in the body. To that extent, I claim that pain, which can be identified in relation to something particular, constitutes a more manageable entity because it can be explained in reference to a specific object, act or event. Even though a person experiencing pain may find it difficult to understand and communicate this pain, a medical language of physical identification may step in as a source of validation for the pain; it offers a form of communication that is rendered understandable. The medical framework creates validity by monopolizing the communication and, in doing so, it reaches the limits of its own possibilities for communication. What is outside the perimeter of medical communication is thus outside the frame of validity, unless the medical communication specifically draws attention to the area in question as being inadequately explored. However, as I point out in this chapter, different locations of pain in everyday life facilitate communication; these locations are tied to objects, events and acts.

The Presence of Pain

In cases where a stroke has caused paralysis, pain may be located in the “dead weight” of the paralyzed body part. Mr. Jensen explains:

(Mr. Jensen) When you're paralyzed, then this one (*lifts his left arm with his right*) is just as heavy as an anvil. It's not like you can do like this (*makes a gesture of lifting with his right hand*); this one (the left) is really heavy. So you're really drooping.

The drooping of Mr. Jensen's left arm causes severe pain in his shoulder. He does not only experience the paralysis of his arm as an inability to do something in particular, but also as a “dead weight” that makes his everyday life increasingly difficult and potentially painful. This way of viewing paralysis as the pain of “dead weight” is often forgotten; in popular culture, functionality comes to play the major part in defining the experience of paralysis. The paralysis of Mr. Jensen's arm does not only make its “dys-appearance” (Leder 1990) felt by its lack of functionality but also, increasingly, by the constant weight that accompanies it. Having to carry this weight makes his shoulder sore. The common description of paralysis as a “burden” is physically confirmed in this instance, but it also highlights how the burden is one of material substance. The paralyzed arm has to be moved around, placed and re-placed into certain positions in order for the blood to circulate, and it must be washed and constantly monitored to make sure it does not cause

trouble for the rest of his body. The paralysis thus emphasizes Mr. Jensen's arm, and makes it hard for him to forget the events that caused the paralysis.

In addition to having to take the arm into consideration during his daily routine, Mr. Jensen has to visit a physiotherapist once a week; there, his arm is treated so that it does not start having muscular spasms that would make it curl inwards; the arm is given Botox injections once every third month to prevent these spasms. Mr. and Mrs. Jensen insist that they can control the pain caused by Mr. Jensen's paralyzed arm. Mrs. Jensen, in particular, is happy to say that Mr. Jensen is currently not taking any painkillers as part of his already extensive pharmaceutical consumption. But Mr. Jensen's arm is the location that poses a very real threat of pain. In that sense, the arm as an object provides a corporeal location for any potential pain, which is immediately communicable. At the same time, the pain may also be located in acts related to the arm – or more specifically, in acts not performed; e.g., not going to the physical therapist, not receiving Botox injections, not monitoring the arm, etc. Yet the arm is not just a demanding and attention-seeking presence threatening Mr. Jensen with pain; it may also cause Mr. Jensen to lose his balance and fall. This has happened a couple of times, which has caused pain in a number of other areas of his body. As Mrs. Jensen explains:

(Mrs. Jensen) Mr. Jensen has fallen in the bathroom a couple of times, and he can't really help himself get up. (...) It's happened that I've come home and he's been lying there swimming in blood, and then I had to drive him to the emergency department. Once, he fell and fractured his elbow...but now, he's going to get one of those emergency-call devices, either on his arm or his neck.

Mr. Jensen falling because of a lack of balance seems to be a difficult factor to manage, and the pain following such a fall is thus unavoidable. Paradoxically, the emergency-call alarm that Mrs. Jensen refers to might be placed on the paralyzed arm – somewhat emblematically pointing to the fact that Mr. Jensen's arm really does call for attention.

In the case of Mr. Jensen, pain has a corporeal location via his paralyzed arm. However, it is not the pain of the arm itself (it is numb) that makes it a location of pain – rather, it is how it causes pain in other areas of his body. The arm holds a constant threat of pain that has to be managed by tending to the arm; thus, it constantly makes itself known as the

primary location of pain that may cause painful events. At the same time, the paralyzed arm is a visible indicator of Mr. Jensen's pain. As mentioned in relation to paralysis, there is often a focus on the loss of functionality, but in this case, the fact that Mr. Jensen's paralyzed arm causes him pain is immediately communicable in reference to the medical diagnosis of paralysis.

Pain and Sleep – Pain as Sleep

For those of my informants who experience pain regularly, sleep is a much-welcome retreat; at least, when they can sleep. However, in many instances, my informants expressed how sleep exacerbates their sensation of pain and makes waking up a less-than-pleasant experience. When a person is asleep, he/she is not aware of the hurt that he may inflict on himself: lying crooked in bed at night might be reflected in the experience of an everyday life with back pain and, depending on the severity of the stroke, having a body that already more-or-less forces one to try to obtain a new relationship with the world through a "changed" body does not make sleep a benevolent character that alleviates pain, but may be what seems to ensure it. From a phenomenological point of view, sleep is a "radical disappearance" (Williams 2005, 68), allowing no room for the conscious management of the body's positioning; thus, the considerations a person may have during waking hours are cast aside during sleep. Furthermore, in such a context, the fatigue that may lead to sleep has an impact, as there is a risk of not being in the right place when sleep takes over the body. This prompted many of my informants to initially experiment with where they fell asleep, which simultaneously resulted in limiting their range of movement. Mr. Nielsen, for instance, has a reclining chair in which he can sit upright or adjust to have a footrest. He often falls asleep in this chair in front of the television at night, and it is the place where he spends most of his waking hours during the day. Before getting this chair, he used to spend most of his time in bed or sitting on a converted garden chair, but then the municipality provided him with a chair that would allow him to rest his legs. As Mrs. Nielsen says:

(Mrs. Nielsen) We succeeded in getting a chair where you just have to push a button and then the footrest goes up or down. It's really good, and then he can lie down and sleep. That's where he takes a nap during the day. Otherwise, he has to go into the bedroom and pull up his legs, take off his shoes and he wears a splint (that has to be taken off) and so on and so on.

Ever since they received the chair, the Niensens have had much of their house modified. The kitchen was re-modeled; they got new adjustable beds, and solid handrails were placed all over the house. Mrs. Nielsen insisted that these alterations were primarily initiated because she noticed that, after first returning home from the hospital, Mr. Nielsen was extremely fatigued; this fatigue was reflected in his inability to be anywhere without falling asleep. Mrs. Nielsen tells me:

(Mrs. Nielsen) He has to be rested when we go somewhere and, although he's always been a lazy oaf³¹, he's never been as fatigued as he is now...that's obvious. We had thought that it would gradually go away, but I think it's the same. It's not quite the same, though, because when he first returned [home from the hospital], he could bloody well fall asleep when he put a cup to his mouth...that's completely outrageous, but I guess you know that. You tell yourself "You can't do that; you simply can't." He doesn't do things like that anymore, but he does lean his head back several times during the day, or he just sits and lets his head fall forward.

Sleep is the event that has to be taken into account, as it has the potential to cause pain. Although the severity of Mr. Nielsen's fatigue has slightly changed since he first had the stroke, his fatigue becomes less pronounced when it is controlled within the house. In essence, it does not matter whether Mr. Nielsen falls asleep in his special chair, as this chair removes the emphasis on fatigue as an issue that has to be handled – because it *is* being managed. The example of Mr. and Mrs. Nielsen shows how their life together is ordered around his fatigue, and it also shows how such a life must be ordered so that Mr. Nielsen does not experience pain during/after sleeping. As in the previous example of Mr. Jensen, pain is a constant threat that, first and foremost, has to be handled by establishing its possible locations. Locating pain as potentially having been caused by sleep makes the pain more manageable and facilitates a possible intervention; i.e., getting a chair that Mr. Nielsen can fall asleep in without waking up in pain. The threat of pain is not something that Mr. Nielsen or Mr. Jensen can eliminate; instead, it is a threat that follows them around and forces them to accommodate potential pain.

³¹ There is no exact translation for the Danish word "snøbel", which is both derogatory and loving; it is an adjective that indicates a lazy but charming person.

Painful Transitions

In slight opposition to the Nielsens, Ms. Petersen is transforming her home to eliminate the experiences of both fatigue and pain – not by accommodating these sensations, but by getting rid of everything that relates to her “old life” with the sensations. When I talked to her, she told me how she is discarding numerous material objects in her home that remind her of her fatigue and pain, and replacing them with new objects that are not related to alleviating her of those sensations; sensations that can be somewhat intense. As she explains it:

(Ms. Petersen)...when I get very fatigued, and if I take a wrong step, or unintentionally place my right foot underneath the carpet, then there's no force in the left foot to help me keep my balance – then I simply fall. Had it been in the middle of the day or in the morning, then the left foot would have been able to support me. It simply can't do that in the evening when I'm fatigued, and so I fall. I get all listless in my body. It's like getting hit in the head...you simply have to focus and then your body gets all listless. Heavy and listless.

In spite of the problems she describes in relation to her experience of fatigue, particularly during the evenings, Ms. Petersen does not want to have any objects in her home that are tied to her fatigue or potential pain – she even frowns upon objects that may ensure her stability:

(Ms. Petersen) ...I don't want a wheelchair...no way. Then I just feel even more... (*she looks at her rollator*³²) – it's because I'm going to Spain (to the treatment center, Montebello), then I'm going to bring my rollator. Otherwise, I don't really use it because it's actually somewhat dangerous when taking the bus. (...) If I'm going by bus and there's just a small gap and the wheels accidentally slip into the gap, then you fall. I've tried it, and I was very close to falling. I don't want any assistive devices because I have to take care of myself. I live alone and have to be by myself. I'm not done living at the age of 53.

Even though the assistive devices might make her everyday life easier, they are framed as devices that would prevent her from taking care of herself in the way she wants to. By implying that the rollator is dangerous and might possibly cause Ms. Petersen to get hurt, it becomes a symbol of how assistive objects are not actually assisting her as much as they are threatening her attempts to construct a new way of life. A life that is not directly comparable to her old life, but nevertheless a life in which she is capable of “taking care of herself” – moving away from a life of depression. She is getting rid of numerous objects in

³² Also called a *wheeled walker*.

her home because she sees them as related to her former life, but they are essentially things that she has been dependent on and that have been relieving her physical pain. For example, she is trying to quit smoking, cut down on the medication she takes (even the pills she was taking for a back injury before the stroke) and get rid of the old furniture where she used to rest. In essence, Ms. Petersen is slowly, but steadily, removing all objects of dependence; in doing so, she is attempting to get rid of her current state of being.

What is so striking is how Ms. Petersen manages her fatigue and pain by refusing to accommodate them. By resisting the objects related to relieving the fatigue and pain in her former life, she locates the pain and fatigue within the objects. And, in a baffling inversion, fatigue and pain are located in the objects that are supposed to alleviate her fatigue and pain. At the same time, Ms. Petersen seems to be aware that it is risky to get rid of certain objects prematurely, and that her progress hangs in the balance. As she says in the excerpt, she still has her rollator and intends to bring it with her to the treatment center in Spain, but it is obvious that she eventually plans to get rid of the rollator altogether. From a phenomenological point of view, one could argue that the rollator is taking her to Spain; i.e. getting rid of the rollator is one of the reasons for her going. Ms. Petersen knows that she cannot chance a relapse, and that she is taking that risk if she discards all of the locations of pain and fatigue too soon; e.g., getting rid of the rollator, cutting back on her medicine too much. In doing so, she might risk becoming even more dependent on the objects that she locates as the explanation for her pain and fatigue. All of this seems to show that, for Ms. Petersen to return to an “everyday life”, she must create new material circumstances to facilitate this progression. From a Heideggerian viewpoint, this means that the material world is supposed to withdraw into “invisible usefulness” (Harman 2010, 201). Alas, we may wonder whether such a withdrawal is feasible if Ms. Petersen continues to experience as much fatigue and pain as she is now. Furthermore, the question remains whether her attempt to get rid of objects of dependence is going to be compatible with the transition into a new everyday life.

Managing Pain

During the majority of my fieldwork, my informants’ pain and fatigue were presented as two separate entities. Thus, other than when the stroke initially caused paralysis, it is very

seldom blamed for causing their pain. With most of my informants who experience pain, it is something that they have managed for a number of years and, according to them, not necessarily something that has been exacerbated by the stroke. In the interview with 86-year-old Mrs. Eriksen, she described how she is managing this sensation, and how she has made it a part of her life:

(Mrs. Eriksen) Well, I feel pain all the time, but I don't blame that on the stroke. That's from my osteoporosis. I always feel pain in my groin, but that's osteoporosis. I've had that for the past 12 years.

Surprisingly often in my interviews, pain features as something that is both manageable and managed. Far from being a sensation that is expressed as a determinant of my informants' way of life, it is presented as an incorporated feature of everyday life. As Scarry argues, the presence of pain is diffused through the acts of everyday life (Scarry 1985). This also seems to be the case with Mrs. Eriksen, who spends a lot of time performing the simple tasks of everyday life:

(Mrs. Eriksen) If I have to begin something in the early morning...if I just have to change the sheets, then I don't do it all at once. I go in and pull off the bed linens and throw them into the washing machine, and then I go in and vacuum the mattress and then start to make it up again, but I wait to put on the rest of the linens. So I do it in stages, and I do that with everything. I do that for the sake of my back. I don't strain myself. I can't do that anymore.

In a similar fashion, Mrs. Eriksen is very cautious whenever the roads are icy; she tries not to go out then. One episode in particular has become the location that explains her decision:

(Mrs. Eriksen) I was once standing down on the town square (in Albertslund) and wasn't able to cross a snowdrift. I had put my one foot down into the snowdrift and the other one was down in the track where the bus stops, and it was as slippery and smooth as a mirror. I couldn't pull myself out, but then an elderly lady came and gave me a hand so that I could get home. So now I don't go out when there's ice. I don't dare to do so. I'm afraid of what will happen to my hip and such.

Pain and potential immobility are present in Mrs. Eriksen's description and, paradoxically, it is her fear of immobility and pain that causes Mrs. Eriksen to confine herself to her home when it is icy outside. A specific past event, although it did not cause Mrs. Eriksen pain, presents the possibility of pain and a potential loss of functionality.

However, in her everyday life, it is not the pain and potential immobility of which Mrs. Eriksen is most aware; rather, it is her new and recurrent sensation of fatigue. She struggles to adapt to this sensation and, whereas the pain is something she is used to and can manage, her fatigue is a novel and different experience that she does not know how to handle. Yet much of how she handles her fatigue is already incorporated into her routines to avoid pain, such as doing everything in stages. It is only when fatigue presents itself as a hindrance to the stages of these tasks that she particularly notices her fatigue. In that sense, Mrs. Eriksen already takes her fatigue into account in the way she handles her pain; by already making her experiences of pain a determining factor in the way she structures her life, Mrs. Eriksen has created space to handle her fatigue. Yet all of the space that Mrs. Eriksen has created seems to come at the expense of a less-eventful everyday life. Nevertheless, in the interview, it does not seem as though the space or her routines are an issue, but rather the things that keep her occupied throughout the day. Mrs. Eriksen presents a good example of how pain is located in certain acts and in specific events. She knows that she needs to do things in stages in order to avoid pain, and she does so accordingly.

The Ultimate Location

In all the empirical examples I have presented here, different events, acts and objects have been analyzed as locations of pain. As these examples illustrate, pain may be located in multiple places at the same time. It is obvious that, although pain may be located in a variety of different events, acts and objects, the place where all my informants describe the pain is ultimately found in the diagnosable body; a body that, in all of the different examples, has received a diagnosis that is ultimately framed as the root of their pain: Mr. Jensen and Mr. Nielsen have both been indirectly³³ diagnosed with slight paralysis due to their strokes; Ms. Petersen was diagnosed with whiplash after a traffic injury as well as less severe slight paralysis; and Mrs. Eriksen was diagnosed with osteoporosis. In the interviews, their diagnosis steps in as the primary source to validate their pain. A diagnosis is presented as an impish authority inside the body that poses restrictions and punishes a

³³ The British National Health Service writes: "Diagnosing paralysis is not usually necessary if the cause is obvious – for example, if paralysis has occurred after a stroke."
<http://www.nhs.uk/Conditions/paralysis/Pages/Diagnosis.aspx>

person with pain – in some cases, even death – if one does not follow its rules. In effect, the diagnosis becomes a location in and of itself, which has its own agency. As the example with Mrs. Eriksen illustrates, she attributes her pain to her osteoporosis and, in the process of doing so, transforms her symptom into a sign that confirms her diagnosis. As a means to communicate her pain, the diagnosis is an easy explanation, as it presents itself as self-explanatory. But as we have seen in the examples here, as well as in the previous chapters, a diagnosis does not always provide my informants with any idea of how to manage their experiences of pain; instead, ranges of other locations of pain in events, objects or acts are accentuated. Finally, the examples show us that pain, similar to fatigue, has a presence that goes beyond the body, and that the location of this presence makes it somewhat more manageable.

Besides portraying the similarities between pain and fatigue and the way in which studying pain provides an entry into the study of fatigue, this chapter also illustrates how the two experiences are often intertwined. Thus, one may become the location of the other; e.g. fatigue becoming the location of pain. In that sense, this chapter touches upon the difficulties inherent in rigidly separating experiences as distinct.

I have attempted to illustrate how pain may be located in acts, events or objects that provide an explanation for pain. By examining my informants' experiences of pain, I have shown how pain is managed and handled through the de-selection of certain acts, objects or events of everyday life that are located as the cause of pain, as well as through the careful and conscious management of objects, acts or events that cause pain, but that are not possible to de-select.

Being Normal – Stigma and Progress

(Fieldnotes) Following an earlier request from Ms. Petersen, I persuade her to go to IKEA. She suggests that we go to the station together, and she takes her bike along. When she walks with her bike, she uses it to support herself, and her gait appears less strained and more normal, with only a slight wobble as opposed to how she usually walks without the bike. She explains to me that she is very fond of biking – it makes her look normal.

As briefly mentioned in the earlier chapters, the issue of normality is often discussed in the interviews with my informants. While the topic sporadically occurs in interviews with those who are elderly, it is emphasized more in interviews with my younger informants. To “be normal” holds no overtly negative connotations and, in my interviews, it is expressed as a desired state of being. At the same time, none of my informants are able to provide an exact and non-conflicting definition of normality, which seems to suggest that normality is constructed through constant negotiation. A negotiation with multiple actors; i.e., the people and objects surrounding them as well as the event of – and the repercussions of – their stroke.

In this chapter, I illustrate how my informants negotiate normality and, in that respect, also its opposite: stigmatization. I approach this by focusing on my informants’ use of material objects, thereby portraying how my informants’ conceptualization of “normality” is reflected in their use or conscious disuse of objects in their everyday lives. Ultimately, I argue that my informants’ conceptualization of normality is intrinsically tied to a desire to progress from their current situations in life, and thus the concept holds no particular value as specifically normal. Bringing in the theme of location, I show how locating what is normal or non-normal may be a part of the process of illness management after a stroke.

In the excerpt from my fieldnotes above, Ms. Petersen says that she experiences her condition as non-normal. Supporting herself on the bike, she demonstrates how, by using certain postures and actions, she can look and behave normally; she attempts to incorporate these actions into her everyday life. Her account of how she re-learned to ride a bike is a happy tale of trial and error, which eventually results in her completely mastering her bike again as well as finding a new joy in cycling. As she told me during our

conversation, she hardly goes anywhere without her bike now, as she is uncomfortable in situations if her bike is not nearby, such as when she is shopping:

(Ms. Petersen) It's when people look at you and you can see their facial expressions, and you can see what they feel and what they think...that's ugly (the experience). I feel like telling them, "I god dammit did not ask for this." (...) I don't look like someone of 53, but people, they sort of say, "Oh, who is that spastic?" – I'm allowed to use that word because I probably felt that way myself...I could imagine. (...)

(MA) *Do you think that people judge you?*

(Ms. Petersen) They judge me, yes. They judge before they're aware of what it is they're actually judging. You could say that I've thought like that before, "Well, okay", but it's not like I judge people on it...that they're not worth having anything to do with when something is wrong with them. I'm probably more curious – "What's causing them to walk like that or look like that?" – but then I can feel those prejudices with people, when you're not entirely normal and (can't) walk normally, then you're – hmm... I feel that a lot, and it's uncomfortable. I haven't thought about that before. You can see it in people – that it's like, they move away from you, thinking, "What if it's contagious?"

The obvious stigmatization that Ms. Petersen experiences is quite closely tied to her concept of a former self, yet she experiences being stigmatized as inappropriate due to her belief that there is a moral aspect to it. This close association between morals and stigma also presents itself in the literature on stigma (Goffman 2009, 32), and it highlights the inherent correspondence between conceptualizations of illness/disease/disability and morality. As shown in the first part of the thesis, fatigue as a symptom of Neurasthenia and Acedia illustrates how an assumed somatic condition seldom loses its moral appendage³⁴.

This moral dimension of the stigma is counteracted by Ms. Petersen's insistence that the people who she feels are judging and stigmatizing her should ask her about her condition instead of looking at her disapprovingly. That way, she could tell them about her stroke, potentially repudiating their moral judgment by pointing out the pathology of her condition. In essence, she wants to invoke compassion by making reference to her lack of culpability for her condition, which would simultaneously make her less "contagious" or dangerous to other people.

³⁴ Similarly, a number of scholars address the stigma of cancer and HIV as inherently moral, as it relates to certain judgments about lifestyle habits or promiscuity; see (Chapple, Ziebland, and McPherson 2004) as well as (Altman 1986) and (Castro and Farmer 2005).

However, it is not only to convince other people of her normality that her bike becomes an important object. When she walks with her bike, Ms. Petersen may experience short intervals where she feels that her physical functionality has been completely re-established. She cherishes those moments, which give her hope that she will be able to walk normally again:

(Ms. Petersen)...Oh yes, by the way, I told my physiotherapist about that, that when I wake up in the morning, before having to fix everything, I could wake up feeling like my left leg is normal. It's like, "Wow." It stays with me, but just as soon as I get my entire body started, it comes back again. (...) Now I'm going to go to Montebello, and maybe I can get some rehabilitation training so that I can walk more normally again...

It is obvious that, for Ms. Petersen, trying to get better means becoming more normal. In this process of reaching normality, a number of material objects are either used more, such as her bike, or used less; her relationship with these objects is the manifestation of her progress towards normality. As previously explored in the chapter "Locating Pain", she is eliminating objects of dependence as well as habits that she does not believe promote progress. In effect, she is not only attempting to get rid of things but is also trying to stop doing things that make her feel non-normal. Doing so will ensure her progress, and thus make her more normal. This process of transition has been underway for some time, as Ms. Petersen explains it, along with an extended period of discontent and depression. The event that triggered the process of transition is presented as the sudden disbursement of a large sum of money from her insurance company. When I visited her, she had just finished having her living room painted and had bought new furniture from IKEA, which had just been set up, along with a new TV. When I asked her when she thought she last had a good day, she told me about the day she realized she would be getting money from the insurance company, and the day when she actually received it. The money became her possibility of a new beginning – a beginning that will eventually make her "more normal".

In contrast to Ms. Petersen, Mrs. Henriksen interacts with material objects in a completely different way. Mrs. Henriksen, who is about the same age as Ms. Petersen, incorporates many things into her daily life that confirm her status as ill and thus non-normal. When I spoke to Mrs. Henriksen, she explained how, before the stroke, she had been diagnosed

with the umbrella condition fibromyalgia. Getting the diagnosis had not been at all easy, and she had to consult several different doctors a number of times before receiving one. She ended up having to go to another municipality, where a doctor was willing to conduct a tender point test. As she explained, this doctor is renowned for being a strong proponent of the diagnosis, and is presumably more prone to diagnosing patients with fibromyalgia. In similarity with her fibromyalgia diagnosis Mrs. Henriksen's experience of having had a stroke is not supported directly by the medical establishment, although Mrs. Henriksen has been hospitalized due to the suspicion of a stroke. As she eventually told me, the diagnosis was never specifically stated in her patient charts and, despite several tests, there is no specific evidence to support her experience. Yet Mrs. Henriksen is utterly convinced that she has had a stroke. Knowing herself that there is something "wrong" with her, she explains that convincing other people of her illness – but not having the formal diagnosis per se – is extremely difficult.

Mrs. Henriksen employs a wide range of tools and assistive devices in her everyday life, and she describes to me all of the different tools she sometimes uses to make her everyday life easier: she bought a special chair she can sit on while preparing food in the kitchen; a potato peeler designed for people with gangrene; and last but not least, she received a rollator that she sometimes brings along with her to shop:

(Mrs. Henriksen)...sometimes, I can feel that my hip and my leg are taunting me, and then I know that it's going to be a "long" trip to Bilka (a grocery store). So I might bring my rollator or my cane. Then I may also see that people walk around thinking, "Yesterday, she didn't walk with anything, but she's walking with something today." No, but the problem is that today just isn't yesterday for me.

She experiences that not bringing the rollator every time she shops confuses some people who she sees regularly. Also, as she explained, the rollator was provided by the municipality and was only lent to her for a short period of time, which is now long past. She is fully aware that she ought to return it, but because she went through a lot of trouble to convince the municipality that she needed it, she holds on to it – she does not know when she might need it again. The rollator is now kept in the sunroom for the few occasions when she might use it:

(Mrs. Henriksen) My rollator is out in the sunroom because then it doesn't take up so much space. Many people tell me that if you don't use it regularly, you should give it back, but I can't know how I'll feel tomorrow or during the winter.

Like Ms. Petersen, Mrs. Henriksen does not feel capable of returning to a normal everyday life. Still, whereas Ms. Petersen's diagnosis was confirmed and thus not something she had to fight for, Mrs. Henriksen struggles to explain to people what is wrong with her. Not feeling as though the medical establishment supports her makes it even harder, and Mrs. Henriksen attempts to construct different logics for how and why she feels like she does now. In many cases, she refers to her physiotherapist as the person who has provided her with some answers, while at other times, she refers to her caseworker at the municipality. His acknowledgement of her physical incapacity is reflected in how he was the one who authorized her to get crutches and a wheelchair from the municipality. Furthermore, it was he who allowed her to go to a municipal office closer to her home to receive her monthly benefits. Thus, in seeking recognition for her experience of having a condition, Mrs. Henriksen is also trying to get some answers. In constructing her own logic about her condition, she seems to have certain points of reference through which she constructs this logic, yet they are not supported by the medical establishment, which makes it harder to convince other people that she actually has a condition. As analyzed in the chapter "Locating Pain", Mrs. Henriksen is still operating within a medical framework, but because her condition cannot be physically located, she does not receive support from the actors connected to this framework – unless she fully accepts that her condition is instead mental in nature. With the absence of a medical diagnosis, Mrs. Henriksen finds it difficult to obtain broad acknowledgement of her condition, and thereby the people who accept her diagnosis – as well as the objects that point to her having a specific illness – become essential in the construction of her illness.

With regard to my informants' use of assistive devices, one sees the obvious differences between how they present themselves. While Ms. Petersen uses the bike to make her look "normal", Mrs. Henriksen uses different remedies to accentuate a physical deficiency that she does not otherwise visibly display and which makes her look different from most other people her age. In other words, when Mrs. Henriksen, who is in her mid-forties, walks with a rollator or with a cane, it highlights her illness. But not using her cane or the

rollator the following day (presumably) alters her illness in the eyes of others, making it a mental rather than a physical condition. However, Mrs. Henriksen's use of assistive devices also relates to how she experiences her illness as a seasonal or daily occurrence that comes and goes. The unpredictability of her illness – i.e., having some good days, where she can walk without her cane or the rollator, and thus appear normal – illustrates how she is situated in what I would call – inspired by Kleinman (Kleinman 1988a) – a “sickness limbo”. For Mrs. Henriksen, this means that the inability to have her illness articulated as a recognized disease forces her to accentuate her experience of illness. This also pertains to cases where she is less affected by it, so as to provide for its institutional acknowledgement. In that sense, through her use of objects, Mrs. Henriksen is attempting to attain a kind of diseased normality – replicating what she thinks a disease looks like via these objects. When Mrs. Henriksen persuasively explains her disease, she does not focus on the stroke itself, but rather on a plethora of different earlier events: having her five children; her first child getting beaten up; losing contact with her second child; having had symphysis pubis dysfunction (SPD); working when feeling chronically ill, etc. – all of which amount to the stroke being primarily positioned as one event in the midst of several other events.

Mrs. Henriksen's condition of being ill has to be sustained so that she can have her illness recognized as a physical disease. Therefore, she rarely mentioned the possibility of getting better, except when she revealed that she feels completely symptom-free when visiting friends who live in the countryside. But she quickly brushed aside the comment, saying that she cannot afford to live there and that her kids would not like it. In a similar fashion, Mrs. Henriksen did not talk much about a hope to eliminate her fatigue, as some of my other informants did. The fatigue was already such an intrinsic part of her everyday life, and also the clearest indication that she had had a stroke, which she was still trying to get medically recognized. Framed by one of Sarah Nettleton's informants in the article “Enigmatic Illness” (Nettleton et al. 2004), the apothegm of “no diagnosis, no prognosis” seems to apply to Mrs. Henriksen. If there is no diagnosis – i.e., the medical acknowledgement that the stroke took place – yet all of the symptoms of an experienceable illness exist, then how does one overcome the sensation? In Mrs. Henriksen's case, it seems as though she is searching for medical recognition via her symptoms and trying to provide

an explanation for her experience, while also attempting to convince other people of her diseased normality through her use of objects.

The Stigma

Both Ms. Petersen and Mrs. Henriksen told me that they feel their conditions are stigmatizing. However, the nature of the stigma is somewhat different in each case, and thus there is an immense difference in the nature of their presentation of normality.

Specifically, the examples of Mrs. Henriksen and Ms. Petersen suggest that conceptualizations of normality or stigma are not static or constant. The approach of focusing primarily on the subjective experience of having a stigma – and thus on one's definition of normality – has been met with criticism in recent years; possibly, for being too focused on the individual perception of stigma as opposed to the larger economic and political processes upon which stigma is based (Parker and Aggleton 2003). Nevertheless, this approach makes way for an understanding of stigma as something fluctuating and dependent on specific situations in which the stigma presents itself, either physically or through the use of objects. Thus, if Mrs. Henriksen chooses to not use any of her assistive devices for an extended period of time, she is thereby able to be physically unstigmatized, whereas using them only sporadically positions her to receive the potentially worse stigma of being mentally ill. But in Mrs. Henriksen's case, she has to embrace the stigma, as it is a possible gateway to the potential acknowledgement of and cure for her condition. Thus, and paradoxically, her route to becoming normal is to attain a certain stigma that will eventually give her the desired diagnosis.

Whereas Mrs. Henriksen is fighting to have her illness experience acknowledged as a disease, Ms. Petersen is struggling to get rid of the stigma related to her illness; because their individual stigmas are discernible to very different degrees, Mrs. Henriksen may thus feel a very different kind of stigma than Ms. Petersen. As previously mentioned, Mrs. Henriksen received the diagnosis of fibromyalgia after a long period of suffering from chronic diffuse pain, but she does not feel as though most people understand her illness; therefore, she prefers not to explain it to them.

At the same time, Ms. Petersen attempts to combat her fatigue through the use of material objects. For instance, when she returns from shopping and goes inside the house with her groceries, she leaves her bike unlocked to ensure that she will go out again instead of falling asleep on the couch. Thus, with the conviction that she might lose her bike – the one remedy that she claims makes her feel normal – she attempts to counteract her fatigue. And in doing so, the opposition between her fatigue and normality is immediately evident. In a rather paradoxical twist, the bike becomes what removes the limp from her walk – and thus, removes what she believes makes people stare at her – while it is also what calls her to action and pushes her away from fatigue. In essence, the bike becomes a tool of normality, both from her own point of view as well as from the point of view that she assumes others to have. It is a remedy against pathology in the broadest sense: the bike does not only make Ms. Petersen experience less stigmatization, it also helps her believe she is making progress. The bike offers a small glimmer of being normal, which she thereby constantly evokes as a way to transcend her experience of the stigma.

When I met Ms. Petersen, she had just gone shopping at IKEA, and she wanted to go back to buy more new stuff for her home when we finished the interview. Having to go twice did not concern her, as she was adamant that she needs to create an atmosphere in which she is not burdened by the things in her house. Things that signal her old – and less-favored life – and not the life she wants to have now, after her stroke. She uses her bike to transport all of the things she buys at IKEA back home.

Adding to the overall argument about location, these two examples portray how certain objects, events and acts may also be configured as locations through the informants' conceptualizations of normality. Whereas Ms. Petersen discards certain objects and incorporates others in order to make herself appear normal, Mrs. Henriksen uses objects to prove her illness and thus to be ill in a normal way. Mrs. Henriksen's example illuminates the way in which getting a medical acknowledgement that confirms the experience of her illness is essential for her sense of progress, and how certain objects become an important part of the quest for an acknowledgement of her condition in general. In other words, with both Mrs. Henriksen and Ms. Petersen, their fatigue and normality/non-normality may be located within the objects that they use. At the same

time, these locations make their illness experiences seem to be more within their own control.

This “Other” Brain of Mine

(Mrs. Nielsen) It’s strange what such a brain can do. I know that it’s not what Mr. Nielsen means...

In the following chapter I explore my informants’ notion of their brain. I argue that they operate with a distinction between their “brain” and their “self”. By turning to the psychoanalytical notion of the “Other” I will argue that my informants try to handle the brain through different practices that render the brain, as an Other, manageable. Among these practices I emphasize the use of medical language and the practice of referring to medical professionals. I present the brain as both an invading force on one’s sense of self and as an integral part of this self.

The Other

The concept of the Other has been widely used in a range of theoretical contexts. From Hegel’s dialectics (Hegel 1998 [1807]) to Husserl’s phenomenology (Husserl 1947 [1931]), the Other has had a prominent place in continental philosophy. With the notion of the radical Other as expounded on by existentialism (Levinas 1979 [1961]) and psychoanalysis (Lacan 1999 [1966]), the concept was transformed to the Other that is now an established feature of the major branches of gender studies (Butler 1999 [1990]) and post-colonial studies (Said 1979). In spite of the transition set in motion by existentialism and Lacan, the Other, as a concept, is, and has been since Hegel, a substantial character that is presented as constituting one’s sense of self, and it is as such that the concept has had its most significant impact on scholarly work in the social sciences in the last hundred years.

Nonetheless, it is the psychoanalytical notion of the Other, as conveyed by Lacan, which is central to this chapter. In the following paragraphs I will discuss the possibilities of viewing the brain as an Other through the lens of psychoanalysis. There is mainly one reason for this; i.e. that psychoanalysis deals with the Other as an intrinsic part of oneself. This part of oneself, which is repressed, serves as the explanation for why things are as they are. In essence the Other is a matter of the unconscious. Being of the unconscious the Other is also exotic. It has another language, other customs etc., which are immensely difficult to decipher, but seeing that it is part of oneself, can either be attempted to be deciphered or

repressed. According to psychoanalysis, the last mentioned is most often the case (Freud 2003 [1919]).

A central premise of psychoanalysis is that the subject is *split*. According to Freud, what constitutes the split of subjectivity is best explained by reference to the relation between the *heimlich* (*concealed*) and the *unheimlich* (*uncanny*), which discloses the fragmentation of the body; a fragmentation repressed and thus essentially heimlich but which in its repression becomes unheimlich (Freud 2003 [1919]). Also presented as the mirror-stage in the writings of Lacan, the split of subjectivity occurs at the moment when the body becomes heimlich, which is the crucial point in which the fragmentation ends and where the body appears as a whole entity (Lacan 1999 [1966], 92-99). In that sense the split of subjectivity arises with subjectivity. This is not far from the Hegelian dialectics concerning the subject's emergence from the object, but the essential point, which separates psychoanalysis from hegelianism, is found particularly in one important distinction; the Other is always already I. I am always already Other, and the sudden occurrence of I does not change this fact, but represses it so that I can appear as I. It is exactly in this description that we find how the Other, being in fact I, presents the unresolvable as well as constitutive point of subjectivity. In essence, the psychoanalytical subject is constituted by its own impossibility, and the Other figures as an essential character of this impossibility.

However, the Other may be extrapolated from the unconscious and assume a very corporeal character. To provide an example, Žižek portrays in *Tarrying with the Negative* (Žižek 1993), how xenophobia and anti-Semitism relates to the national identification with a Nation-Thing. The Nation-Thing, or just Thing, is best described as that, which is considered to be the knot that ties certain people together in a community. It may be a way of life, which is impossible to describe or elucidate, as doing so would reveal the inconsistency of the notion. In essence, it is a notion relating to the organization of enjoyment, which is constantly disturbed by the Other as the Other possesses the threat of robbing one of this Thing. It threatens one's particular way of life; e.g. the notion of a Jewish conspiracy. However, the Other is exactly what facilitates and creates this unobtainable Thing by being constituted as the Other. In effect, the Thing is possessed through its potential absence – through it being stolen by the Other – and this is the

illusion that seems to resolve the split subjectivity. Yet the problem remains that this rift between me and the Other is still inherently internal.

In order to fully understand how this rift is incorporated within the life of the split subject, it is necessary to look at how the subject, from a psychoanalytical perspective, interacts within different modes of reality; more exactly three different modes of reality: the symbolic order, the imaginary and the Real.

To put it simply, the symbolic order is that, which provides an immediate identity to the subject; it is the name, the age, gender etc. that presents the subject as difference within society (Butler 2005, 90). However, to be one's name, age or gender does not necessarily provide a locus through which the subject can understand him/herself – one is always something more than one's symbolic identity. This, something more/locus, is provided by the imaginary. The imaginary is the locus that supports one's symbolic identity. It is what allows an assemblage of the subject as pure difference in the symbolic order, and thus the imaginary is what is the true "self" behind one's existence within the symbolic order. In that sense the imaginary is what fills in the gaps of the symbolic order, as well as it is that which produces subjective meaning from the symbolic order. Yet, the imaginary is not a stable entity but lives by the insecurity of the split subjectivity – thus it is what points towards resolving the split, and in doing so it becomes the place where the psychoanalytically important concept of *desire* (*jouissance*) is to be found. In short, this desire is a desire towards solving the split of subjectivity, but as a central maxim of psychoanalysis, desire is always facilitated by its own impossibility. In most cases, this desire is directed towards resolving *objet a*, which is what is an obstacle to one's fulfillment of desire (enjoyment). But again, *objet a*, being the impossible object of enjoyment is unobtainable as the very premise of its existence, and thus resolving the split of subjectivity through resolving *objet a*, is equally impossible. However, solving this split through *objet a* is a pleasure in pain in which the identification of *objet a*, or identification with that or those who have access to *objet a* (what was referred to as the big Other in the chapter "The Communal Narrative"), becomes crucial for the subject. Finally, what may disturb this quest for the *objet a* is the negative impact of the Real, which is that which is impossible to integrate within the symbolic order, and as such un-representable. The Real

is what points to the randomness of the symbolic order, as well as to the disintegration of the imaginary; to the disintegration of reality.

The figure of the Other is configured within, and configures, these three dimensions. The Other may be perceived as a threat to one's symbolic and imaginary place in society, while it simultaneously is that which makes the specific organization of enjoyment possible within a symbolic order, or within a community. In that sense, the Other may be comparable to the *objet a*, the character of enjoyment that interrupts one's unique fulfillment of enjoyment in the world, but at the same time confirming the existence of enjoyment and thus solving the split of subjectivity (Žižek 2008, 56). However, the Other may also be a figure that is closely associated with the Real, as will be further explored later. Most importantly the Other, on the symbolic and imaginary level of subjective reality, disturbs as well as confirms the possible existence of a subjectivity that is not split; of a whole self.

The Self and the Other

In the abovementioned description of the psychoanalytical Other, there is a constant presence of an I or of a self, which the Other relates to. In *Inventing Our Selves: Psychology, Power and Personhood* (Rose 1998), foucauldian sociologist Nikolas Rose presents the concept of self-hood as relating to the idea of an autonomous subject, exploring and potentially finding him/herself. According to Rose, contrary to popular conception, the concept of selfhood is more historical than ontological; this is the premise for his book containing numerous genealogical essays, amongst which many are very critical of the historical role of psychoanalysis in the creation of selfhood. Challenging the construction of the conception of selfhood as being a regulatory ideal, Rose sets out to denaturalize the regime of the self, which is presented as inescapable in reference to the contemporary individual (Rose 1998, 2). However, as Rose also argues, this notion of selfhood is such an established phenomenon in contemporary western society that its existence in the lives of people is inescapable. Thus, in an interesting inversion of Rose's deconstruction of the psycho-disciplines – as Rose calls it – one could argue that psychoanalysis becomes even more relevant to incorporate in the analysis of the self.

If we try to turn to the notion of selfhood in relation to the body, feminist philosopher Margrit Shildrick argues that the sensation of unity in one's body can be ascribed to the Western notion of person as the "possessor" of a certain materiality (a term borrowed from English philosopher John Locke) (Shildrick 2001, 48). As Shildrick points out, even in a phenomenological framework, this notion of a certain unity is constantly asserted as that which promises selfhood. Although phenomenology underscores the constancy of an openness in which the construction of selfhood may take place, it contains a "solidification of perception such that we can reflexively experience our embodied selves in more or less consistent ways" (Shildrick 2001, 49). It is for this reason that the body stands out, as Leder puts it, as something *other*, something suddenly "re-membered" in the case of disease or molestation (Leder 1990, 91). To that extent there is, as Shildrick notes:

... a sense in which embodiment, in being symbolically associated with the disruption of the subject, runs the same risk of being ontologically devalued, being seen as potentially monstrous, in phenomenology as it does in more conventional philosophies (Shildrick 2001, 49)

Shildrick argues that this is due to the question of the constitution of an autonomous subject, as it is unclear what to do if one cannot be distinguished from the other as she shows by analyzing the separation of conjoined twins. In essence, to be accepted as a self with a selfhood is basically being distinguishable from the other, and thus to be secure within the body – not being the body (Shildrick 2001, 50). Paraphrasing feminist writer Julia Epstein, this obsession with our body is intrinsically tied to the way we construct our subjectivity and selfhood (Epstein 1995). The "monstrous" body according to Shildrick is what challenges not only the selfhood of the person as the body, but also the entire symbolical order of distinctions between mind and body and bodies between. As Kristeva argues, the appearing body is an ugly body, and quite an opposite to the notion of the self's clean and proper body (Kristeva 1982, 71). Such a body is *abject*, meaning that it disturbs the symbolic order and identity formation of the norm (Kristeva 1982). In that sense, the monstrous appearing body is somewhat ambivalent as it is both the binary opposition of the "normal body", confirming the self-hood of the normal body, but at the same time it is also so human that it is in fact threatening to dissolve this binary opposition. Thus the abjection does not mean total exclusion, but is rather the position of being an Other, though not an absolute other. In an analysis of the body of Venus de Milo, Lennard J. Davis argues in a similar vein, that the disabled body presents a fragmentation

of the body, which is normally repressed, and thus the disabled body becomes stigmatized because of the same “unheimlichkeit” that it represents (Davis 1995). However, to say that the disabled body does not figure within the symbolic order as something else than Real, seems to discount the integral potentialities of the symbolic order. As Žižek argues, there are different modalities of the Real, of which the symbolic real is the reduction of the signifier into a seemingly meaningless entity difficult to understand without reducing it to something simplistic. In essence, it is a somewhat abstract texture, which is reduced to symbols or an empty signifier – making it more digestible in a system where there is no constant interpretation of it. An apt example could be provided by quantum physics and the Einsteinian symbols of $E=mc^2$. Many people have seen this sequence of symbols and acknowledge it as something important, but the concepts behind are difficult to integrate into the symbolic order. The symbols make the symbolic real symbolic – they can be reproduced and integrated within the order of things, although a deeper understanding of the concept underlying the symbols negate and question the symbolic order. In a similar manner, the language of the medical sciences is essentially symbolic. It is what translates the modalities of the Real into the edible and integrable realm of the symbolic. In a medical terminology the monstrous body receives a diagnosis and is spoken of in a language, which allows it space within the symbolic order.

I argue that it is primarily in adopting the language of the medical sciences that the brain begins to stand out as a Being in itself; as something which has not yet been placed at the right place – or which has become disjoint – and thus present in its absence of being a functional tool, but also present in its possibility of becoming such a tool. To that extent, the brain as signified by a medical terminology, which is difficult to access if one does not have the necessary prerequisites (as with quantum physics), ensures the presence of something, which is currently absent. Much in opposition to the notion of the “real” Real, which operates outside a logic of absence and presence, continuously as a negative force within the world, opposing the notion of there being anything absent or present, the symbolic real – as that of a medical terminology – offers the ontological presence of what is currently absent from the symbolic order, or rather it offers the pretense of a symbolic presence behind the absence. It is to that extent that the brain stands out as a presence by being dysfunctional, but still integral to the symbolic order in its capacity of being reduced

to a medical terminology. We might even go as far as to say that such a medical terminology has as a prerequisite for being symbolic real, that it *is* alienating and thus somehow corresponds with a brain, which has turned from, in a Heideggerian sense, a *tool*, into a *thing*³⁵.

But the brain is more than a tool or a thing. As many of my informants argue, and as I will return to shortly, their brains have a will of its own, which directly implicates their Being in the world. In opposition to an arm becoming numb and hereby both constituted as a thing in the same process where it becomes lost as a tool, the brain that my informants speak of is a thing gone astray. It's about balancing the damage that the thing may inflict, specifically the social damage. The brain is the noisy and intolerable neighbor, which one has to accept. You can try to keep his noise down, but he will always be there as a chronic feature of existence, who sometimes rings your bell completely naked asking if he can borrow your toothbrush, and who does so in particular when you have visitors. In essence, the brain becomes a feature, which is not consciously completely alienated, but rather a necessary feature, whose impact one must limit or at least make more tolerable by managing it.

In the following section I will present how the brain appears as an Other in my empirical findings. With the help of psychoanalysis, I will portray how the relationship between the brain and selfhood may be analyzed, and in the process add to the psychoanalytical theoretical approach. I will argue that the notion of the self structures the conscious management of the brain for my informants, and that my informants draw on the notion of self-hood whenever they experience their brain as an Other. As will be shown, this self often becomes somewhat of a consolation in an environment where one's autonomy may seem to have disappeared.

³⁵ This corresponds with the analysis of everyday life in the chapter "A Disrupted Return to Everyday Life", presenting the relation between *vorhandensein* and *zuhandensein*. The tool is that which withdraws into invisible usefulness (*zuhandensein*), whereas the thing is what appears to consciousness as a specific entity in itself (*vorhandensein*)

The Other Brain of Ms. Petersen

I formerly referred to Ms. Petersen in the chapter "A Disrupted Return to Everyday Life" and quoted her saying:

(Ms. Petersen) In the beginning I had both lights on my table turned on, and the television...the sound... It was like I had to make my brain focus on those sounds, because when there was complete quietness, I just couldn't sleep.

In that chapter, I allowed for the quote to represent Ms. Petersen's experience of Angst, but if we look at it once more, Ms. Petersen's brain is a central figure in the quote. In talking about how she has difficulties sleeping at night, her brain is a contributing factor, if not *the* factor, which causes her to find it difficult getting any sleep.

The agency of the brain becomes poignant in this case, as the brain is the feature, which Ms. Petersen has to deal with. She becomes aware of how it is not possible to turn her brain off, so that she can sleep – something she used to be able to do quite easily. This very much relates to the retrospective construction of the brain as an Other – an Other whose existence Ms. Petersen only recently has become extremely aware of, but who has always been there in peaceful and obeying coexistence with selfhood. Her brain needs a certain amount of noise to keep focused on something else, in order for her to be ensured sleep.

At the same time Ms. Petersen's brain makes it difficult for her to focus, and she explains how it has become dreadfully difficult to read. But the brain is also deficit in the sense that it causes her pain. Commenting on how her brain has stopped producing endorphins, she presents the same picture of a brain working against her:

(Ms. Petersen) ...I have "restless leg syndrome" Do you know what that is? It has something to do with your brain not producing endorphines or something else...I can't remember. It's something up in your brain, which your brain does not produce, and which causes your muscles to spasm.

That she experiences her brain as dysfunctional is indicated not only in how it limits her possibility of sleep, but also in the sense that it causes her to feel another part of her body not doing as she wants it to. From a psychoanalytical point of view the stroke is an element of the Real that emphasizes the fragmentation of Ms. Petersen's body – here in particular her brain. In trying to return to the symbolic order, the brain naturally becomes an Other, integrated within the symbolic order as that, which is causing her self to have to behave

differently. The Other is thus a figure that has to be circumvented. However, circumventing her brain as an Other seems to be presented as an established practice for Ms. Petersen ever since she had a whiplash injury as well as a minor brain injury after a car accident some years prior to her stroke:

(Ms. Petersen) Too many things jumbled together, and then I can't focus on anything. Then I forget half of it. I have had to buy a stamp for three days now, and I haven't bought it yet, and it's God damn important.

(MA) *Have you felt like that always?*

(Ms. Petersen) No...no of course there's been something...I had a minor brain injury in connection with my whiplash injury, which means that my short term memory and my concentration isn't great...I have papers saying so. In time, I have learned that if I'm going shopping or something like that, then I write down "1 liter of milk" and "1 liter of milk". I can't write "2 liters of milk", because then I only get one with me back home. It has something to do with the fact that when I'm out shopping with my shopping list then I count the stuff on the list, and it has to match the items I have put in my basket. If it fits, then I've got the stuff I need. If I don't bring a shopping list, then I don't get the things I need. (...) I get tired when I'm down at the mall. I have to walk fast and like "tjit tjit tjit" and then I have to get home, because all of a sudden I'll say "now I don't bother anymore", and then I don't know what I need. It has to be planned very thoroughly before I leave, so that I know exactly what I need. For instance, I know what I need from IKEA today. I'm going to bike over there. I force myself to do that, because then I'll get to use my legs. I know that I need two small tables, one there and one there (*points to her office and to her living room*) and some candles. It'll say so on my shopping list, which means that it'll say 1 table and 1 table and then the number of candles I need. So I really hope that I can pull myself together to do that.

What is of immediate interest is how her brain has become a retrospective Other. Her brain was always an Other, Ms. Petersen was just not as aware of it as she is now. Rather she was able to manage the Other through a range of different practices to such an extent that the Other disappeared completely. Her shopping list is an illuminating example of such practices as it makes the appearance of the Other less visible. In hindsight, the Other was always there, and her previous effort to control the Other is put to the test by the stroke's placement of the Other as a more defining character of her self within the symbolic order. To that extent, the previous Other could be viewed as a less invasive character, retrospectively constructed as someone that did not necessarily stand between one's self and the potential solving of the split of subjectivity – rather it confirmed the existence of a subjectivity with a split that could be solved.

As the quote also illustrates, Ms. Petersen is attempting to manage her brain as well as she is managing other parts of her body; e.g. her legs that need to exercise. But Ms. Petersen's brain doesn't really rest, and so having to manage her brain is a relentless task. Her brain appears as opposed to her self in every waking moment and is even causing other areas of her body, which she would otherwise be able to manage, to become unmanageable e.g. the muscles in her legs getting spasms. This highlights how it is Ms. Petersen's brain, which is causing her to experience a fragmentation of her body. In this fragmentation a self is of considerable importance, as it can manage a brain that may feel like it holds the body hostage.

The Other of Mr. Jensen

We previously met Mr. and Mrs. Jensen in the chapter "The Communal Narrative" as well as in "A Disrupted Return to Everyday Life". To recapitulate, Mr. Jensen has had seven strokes in total, the final one causing him partial paralysis. After the seventh stroke, Mrs. Jensen had an extremely hard time dealing with Mr. Jensen, whom she felt had transformed into another person.

In the following quote, notice how the explanation of Mr. Jensen's brain provides comfort for Mrs. Jensen, but also how this description is interesting, as it is somewhat similar to the explanations offered when explaining the customs and habits of an Other:

(Mrs. Jensen) Before the stroke Mr. Jensen was a happy and outgoing person, and then it all turned around and he became mad and grumpy after the stroke, and now everything is wrong. I was just told (by the doctor) that I had to live with it, but you learn a lot underway. There are certain fights you learn not to take, but you also learn that you can't be too indulgent and keep on saying "oh, it's because he's sick"(...) Nobody tells you what can actually happen. I was explained how Mr. Jensen had an injury in his head and that this was the reason why he had begun to steal. He started going into people's purses, and I was very shocked by that and I had no idea how to cope with it, and so I told our doctor about it, and Mr. Jensen was well aware that something was wrong (...) Our doctor didn't know anything about it and had never experienced it before, and so he sent Mr. Jensen to a psychologist in town, but that didn't really help much. Our salvation, if you might say so, was the hospitalization of Mr. Jensen due to some problems with his coronary artery, which they wanted to operate at the hospital but which they found was too risky. So when he was discharged we had a conversation with the doctor and I told him about the problems with his stealing. I was so far out at that point, Mr. Jensen had been ill for seven years, and I had begun to think "how do I kill him and

get away with it" because I thought the situation was unbearable and he was so unfair. He slept all the time and was never present, and then I became aware that this was totally wrong, and so I told the doctor about my thoughts. So she says that we have to look at it right away and calls a neuropsychologist; a week went by and she spoke a bit with Mr. Jensen and after a couple of minutes she says to Mr. Jensen, that she thinks she ought to speak to me instead. So I went there regularly for a couple of months, and she told me about everything and showed me the scans of Mr. Jensen's brain...how it looked with all the spots and explained to me that "here and here was this and that, which affected behavior and speech and how damaged these spots were". (...) It was like that it all started and where I became aware of how things are located in Mr. Jensen's head now (...)...but it was simply because I didn't know where to get help, and in the meantime it was difficult because he stole from our kids and friends, and then having to tell them to hide away everything because I am bringing a person who steals. But they have managed real well (...) the neuropsychologist also told me that it is not unusual for people to get such behavioral issues. Some become arsonists, and others become sexually deviant, but that's always horrible when discovering something like that, and how do you deal with it? We talk a lot about things now.

In trying to understand Mr. Jensen's behavior, Mrs. Jensen refers to the neuropsychologist, who explains to Mrs. Jensen that Mr. Jensen's brain is the cause for his sudden change of behavior. In essence, why Mr. Jensen has become an Other. As the quote illustrates, there is always someone who has a more direct access to the Other and thus a better understanding of this Other; in this case it is the neuropsychologist.

Mr. Jensen has changed after his stroke, and his surroundings, especially Mrs. Jensen attempts to get accustomed to this change. In effect Mr. Jensen has become an Other, who is inherently unreliable, not only on account of his stealing, but on account of his Otherness, which is explicitly apparent in his stealing. Almost as an ethnographer describing and explaining the rituals and customs of an alien tribe, the neuropsychologist explains why Mr. Jensen is doing what he is doing and needs what he needs – basically why he is behaving like an Other – and in the process of doing so, Mrs. Jensen begins to understand Mr. Jensen as something else. He is now truly an Other; not only his brain but also his self. In effect, Mrs. Jensen attempts to control and construct the self of Mr. Jensen. Aided by Mrs. Jensen, Mr. Jensen attempts to "take back" his selfhood; this is reflected by the way in which he, during the interview, disassociates himself from his brain and in particular from what his brain has caused him to do – to steal. In that sense, for Mr.

Jensen, it has become a question of managing his brain, and his ability to do so becomes visible through putting an end to his stealing:

(Mr. Jensen) It was the thing with the stealing, so we really didn’t dare to go (to the treatment centre in Montebello). At that point I had not gotten over that.

As Mr. Jensen expresses in the quote, his former inability to control his stealing caused him and his wife to avoid seeking further treatment at the treatment center Montebello for his paralysis, as he was scared that he might steal from the other patients. In essence, an Other (his brain) was withholding him from seeking further treatment. Whereas Mr. Jensen expresses that he is beyond his period of stealing, Mrs. Jensen is not entirely convinced but follows Mr. Jensen around to make sure that he doesn’t stealing anything:

(Mrs. Jensen) It was hard when we were anywhere telling other people (about Mr. Jensen’s stealing), and at the same time telling Mr. Jensen that it was not to observe him that I always followed him around, but that it was to help him. It took some time for him to understand it, but now there’s hardly anything anymore, but that’s also because I have to help him in the bathroom and such stuff, but it was a huge shock. But we are in control of that now, aren’t we Mr. Jensen?

The example of Mr. and Mrs. Jensen portrays the subtle nuances that are at play. Mrs. Jensen sees Mr. Jensen as an Other but helps Mr. Jensen (re)construct his selfhood, so that he can control his brain, which he sees as an Other. As previously analyzed in “The Communal Narrative”, she supports him with his narratives, and assesses his current state/otherness through his ability to reproduce certain narratives agreed upon. At the same time, it is apparent how Mrs. Jensen, being distrustful of Mr. Jensen, manages his otherness through allying herself with Mr. Jensen’s (re)constructed self; in this alliance she monitors Mr. Jensen and is vigilant that his (re)constructed self remains in control – a large part of this is making sure his (re)constructed self does not change. In that sense, as Mrs. Jensen explains it, the self of Mr. Jensen is that of an “Other” who cannot get too close. Lacan touches upon this issue in his seminars on ethics, arguing that one can only love one’s neighbor, as long as the neighbor is in a proper distance (Lacan 1997 [1955-1956], 186) – and similarly Mr. Jensen’s self is constructed to provide this distance, as proximity reveals the unnerving cracks in the surface – essentially the disintegrating potential of the real. To that extent the (re)construction of a self of Mr. Jensen is part in keeping Mr. Jensen within the symbolic order, although not as a constitutive Other, but as an Other threatening the deformation of the symbolic order; i.e. his self is an Other of the imaginary

real, which as the symbolic real is that which is so unbearably close to the real, that it almost negates the symbolic order. In that sense this Other is on the verge of negating the symbolic order, and the task is to constantly integrate the Other as an Other within the symbolic order.

With the Nielsen couple, we can add to the nuances of the brain’s relation to the self:

(Mrs. Nielsen)...If there is something that interests Mr. Nielsen, it’s Copenhagen, and he can remember everything...there’s nothing wrong with his head. That’s the odd thing, and I think a lot of people think that, and they are awfully wrong.

In the quote Mrs. Nielsen expresses that Mr. Nielsen’s head or brain³⁶ is constantly switching between being the diseased part that is not working and, which has caused his selfhood to be altered, the locus of his former identity – as if a part of his selfhood is locked inside him. This approach is something I often encountered from the spouses, as they would assume that their “former” husband was still “in there”, and argue that his real self would sometimes emerge. On the other hand, the informants, who had had a stroke, were often confused by how their spouses would reduce their selfhood to their brain and would have a hard time trying to deal with the othering of their spouse. This illustrates the fluidity of the notion of selfhood among my informants’ spouses. A self may be othered through the brain, and thus necessarily constructed in order to control the brain (as in the case of the Jensen’s), while the true self may sometimes emerge in certain circumstances.

What the cases of Mr. and Mrs. Nielsen as well as Mr. and Mrs. Jensen show is that the construction of the self is distributed onto different actors, and constructed by these with very different intents; essentially that selfhood is a social affair.

The Integration of the Brain

Mrs. Henriksen tries to embrace her new relationship to her brain by allowing her self to listen to her brain:

(Mrs. Henriksen) ...All in all it’s about listening to yourself. I can just feel that I get some things in my head that indicate that now I just have to slow down.

³⁶ The words brain and head are used interchangeably and I have been unable to find any empirical basis for their separation nor a methodological framework, which could account for any difference.

Mrs. Henriksen is now taking her brain into account in a way she hasn't done before. In her case, the brain represents something that she has lost a relation to, a relation that she is attempting to reestablish. The use of a phrase such as "listening to yourself", thus indicates how Mrs. Henriksen's notion of selfhood is tied to her reestablishment of a relationship to her body. In this reestablishment with her body, the brain plays a significant yet tricky part, sometimes being a part of her body, at other times closer to her notion of selfhood than her body "my brain tells my body to do as I want, but my body won't comply", and at other times as something that just won't do as she tells it, thus comparable to an Other. Her brain is configured in relation to the specific situation that she is in, as can be seen in the following quote:

(Mrs. Henriksen) It's an anxiety for things not succeeding, and that I'm left with a problem thinking "how do I solve this". It's not always that I can find it in my head. Then you could say "well everyone feels like that once in a while", and I'm sure they can, I've just never felt it. I've always found a solution to any problem.

This illustrates the way in which Mrs. Henriksen's retrospective relationship to her brain causes her to be disappointed with her current lack of ability – not being able to do as she used to, although her former capabilities exceeded those of others. As seen previously, this sense of a former self is manifested in the narratives and may seem somewhat exaggerated. All of a sudden one's former self was not only performing normally but is reconfigured as having performed extraordinarily. One can only speculate whether this directly reflects the dialectic opposite of the experiences Mrs. Henriksen has now, but it nonetheless seems to be a recurring figure expressing a point in time in which her self was in a satisfactory relationship with her brain and body – working as one unit towards the same goals. Re-attaining this relationship is only possible if Mrs. Henriksen allows room and space for a re-assemblage of this relationship, and much of her daily life is centered on doing so. In that sense the self of Mrs. Henriksen is not an Other through it being the occurrence of a "new" self, but rather because of its appearance as a self; an appearance which is visible because it contrasts her brain and her self. Mrs. Henriksen tries to blur the contrasts, and in doing so, she makes listening to her brain a large part of her everyday life. This everyday life is particularly structured around her experience of fatigue, and she portrays this structuring as the most significant remedy in her re-assemblage of the relationship. Fatigue is to that extent a signal as much as it is a tool in the re-assemblage, becoming the

sign that she is listening to her brain when she plans her activities in accordance with her sensation of fatigue, as well as stops her activities whenever she experiences fatigue. Nonetheless, she does not feel that people, except her closest relatives, understand how she is in need of special care, as the immediate visibility of her condition is non-existent.

(Mrs. Henriksen) No, but it's difficult. It's much easier breaking a leg or your back...people understand that. They don't understand it, if you tell them it's your head, but you know that. For instance, I was at a 50th birthday in February, and thank God I was seated next to a person who had had an apoplexy and who had become partially paralyzed by it, and she also had some difficulties concentrating and we sat and talked. Then suddenly she said "you are getting so quiet", then I told her "I'm really tired right now...just used up."

As Mrs. Henriksen tells the story about the birthday, she emphasizes how she was very happy to sit next to a person who had had a stroke, and thus possibly understood how fatigue was a central part of her re-assemblage. In that sense, whereas physical damages are often portrayed as necessitating rest, Mrs. Henriksen expresses that the invisible mental fatigue, which she is experiencing, does not translate as easily. In this case, Mrs. Henriksen is attempting to allow her brain, as an Other, room in her everyday life. This Other is eventually sought re-integrated but can only be so if she listens to it and behaves according to its wishes. At the same time, as illustrated in the chapter "Being Normal", this might also be due to the fact that there is no doctor who can affirm the existence of the Other of Mrs. Jensen's brain. She has received no formal diagnosis, and thus her way of integrating and allowing space for the Other, is the only way for it either to appear more obviously, so as to become medically recognized, or to eventually transform it and her self, in order for her to get a new everyday life. With Mrs. Henriksen we thus see how she has to balance the Other. On the one hand Mrs. Henriksen's Other, is what verifies her experience of illness to others, while it is also what may make her entire being an Other. In that sense the Other of Mrs. Henriksen is welcomed by her, as this welcoming facilitates both an eventual re-integration with her self as well as a recognition of her disease.

The Disciplined Other

While the case of Mrs. Henriksen represents an attempt at re-assembling her brain to her self, the case of Ms. Krogh represents an extremely separated notion of the brain and the

self, where both her self and her brain are presented as Others. In that sense they are seen as entities that have to be kept in a balance more than re-assembled:

(Ms. Krogh) I also have an aneurysmal bone cyst (in her leg), but that's the issue, because the brain has to have peace, and the legs have to move. Then I have to find a balance, where I don't get tired.

There are three different actors at stake in the above quote: her brain, her legs and her self. Her self gets tired, her legs need activity, and her brain needs rest. In order to trick her brain into being active, she has created different rules and dogmas, which she has to follow, and that force her to be active. She has unplugged her fridge, partly due to an ideological conviction, as well as due to the fact that it necessitates her getting out of the house when she is hungry:

(Ms. Krogh) Yes I'm out every single day. I aim at getting out, because I have to buy my groceries. I have turned off my fridge and my freezer, so I have to get out every day to buy my groceries and see what I want to eat.

(MA) *Why are they turned off?*

(Ms. Krogh) It's a practical matter, because I started thinking that my mother was capable of not having a fridge, and we were six people. We always had lovely food. Then I began thinking, if my mother knew how to do it, then I would try it for a while, also because, frankly, I was rather tired of looking at, and listening to, it. But I think I'm the only one who feels that way. Everybody else can't do it. "It's alright with the freezer" they'll say "but the fridge", but then I tell them "what the hell, I have my garden...honestly, that works perfectly fine". It doesn't have anything to do with... I can pay my bills I just have to see how creative I can be. It becomes a sport. I hardly throw anything out compared to others, and I'm really happy about my system. But there's no one else, yes my grandchild also does it. Well okay, she also works as a chef and gets a lot of her food out, so she doesn't need all that. It's also the fact that one's stomach gets a shock when you pour all that cold stuff down there, then the body needs energy to warm it up. There's a system in it. I feel really great about it.

As she explains earlier in the interview, she feels that she gets strange, if she doesn't go out each and every single day, and although there is not necessarily a social aspect in getting out, it is as much a regime that she follows. This is exemplified when she tells of a trip to the entertainment park Tivoli, which she was supposed to go to with her two sisters. Both of her sisters cancelled due to illness, but Ms. Krogh went anyway – an accomplishment

that she emphasizes that she is very proud of. Getting out is in itself a goal, and the fatigue that follows is thus justified by the goal that she has reached when she has been out:

(Ms. Krogh) If I have been to the public swimming baths, then I have to walk half of the way, because it's over the railway and over the hill and so on. Then I'm really tired when I'm at the public swimming baths. That's once or twice a week...that's what I aim at, because I can feel that it's the right thing.

The regimes allow her to take control of her brain, her self and her body, and provide her with the sense that she is in control of her body and her brain. Fatigue is a signal that she is mastering the relationship between her self, her brain and the rest of her body. To that extent it is not her self, which is mastering her brain and her body, but rather the regimes. She manages her self, her brain and her body through an othering, in which the regimes take over and decide for her.

At night, Ms. Krogh exercises her hand, which was partially paralyzed after her stroke. As she explains it, an especially dedicated physiotherapist filling in for the regular personnel, spent a lot of time stimulating her brain into recognizing her hands' sensory capabilities. Now in order for these capabilities to remain, she continues her exercises, though she has no hopes for any further recovery:

(Ms. Krogh)...I have to...when I sit and watch television at night...then it's handgymnastics, because it sort of just stopped its progress (the hand). Nothing really happens with it any longer.

(MA) *So you don't experience the progress you experienced the first 14 days any longer?*

(Ms. Krogh) No, and I have been told that it's pretty normal that it stops there, so I have to live with that. But I try with exercises and different things, because it ought not get any worse. It has to be kept going. It quickly becomes like that (flaccid)...it doesn't like the cold. It doesn't like that at all.

In short, the exercise of regimes sustains a relationship between the different parts of her being: her self, her body and her brain. While Ms. Krogh is quite clear in describing her regimes and is detailed in her description of how her everyday life is structured, she nonetheless insists that her everyday life is not that structured but dependent on how her body feels:

(Ms. Krogh) I have slaved away in my time, so now I’ve said that my body has to be allowed to decide on its own. Then it can vary when I get up, like today, where it was very early, but most of the time it’s half past eight and then breakfast lasts a couple of hours, writing my diary and reading the newspaper.

This picture of a body deciding on its own seems to be in stark contrast with the way she is constantly administering and managing her body, and in particular regulating the relationship between her brain and her body. It nonetheless presents the way in which, she is trying to obtain a balance between her brain, body and self, albeit this period of listening is constrained to specific periods of time as well as situations.

The regime of Ms. Krogh relates to almost all aspects of life, and the following quote illustrates this point quite well:

(Ms. Krogh) I can’t have that much licorice, so I’ve put a quota on that. If there’s licorice in the house, I can have two a day. I hold on to such things, but otherwise I try to get all the way around in terms of food, and then I bake my own bread, but that’s also because I want my hand to get moving. It’s a food thing for it to do some work.

Everything seems as if it’s placed within a certain rationale that gives her a sense of control. These concepts of disciplinary regimes and control, as allowing one to feel in control of one’s body, are well studied within medical anthropology (Scheper-Hughes and Lock 1987). However, I argue that the case of Ms. Krogh presents how a disciplinary regime may also be a matter of controlling and sustaining a balance between the brain, the body, and the self. In this disciplinary process, the separation between the different parts is not sought resolved; rather the parts are increasingly fixed as specific entities hopefully being able to work together. She initiates regimes that go beyond her selfhood – to control her selfhood and simultaneously her brain. These regimes are what I would call “regimes of the future self”, and thus not as autonomous as one might think them to be.

Returning to the initial theme of the chapter, Ms. Krogh is not only presented with an Other, being her brain, but is, through the regimes, confronted with three different Others; her brain her self, and her body. These are Others that she controls partly by listening to their demands, but for the most part through subjecting them to a disciplinary regime.

The Other is a Brain

All of my informants are acutely aware that there is something wrong with their brain. From a phenomenological point of view, their brain has come to appear as an organic entity in and of itself. However this appearance is different from the appearance of another part of the body, in that the brain is conceived as an extraordinarily central part of selfhood. In most cases, this is reflected in my informants’ ways of distrusting their brain, while simultaneously having to rely on the same. The vocabulary surrounding the brain is often medical, and the medical description facilitates a distancing to the brain, but may concurrently also become inextricable from selfhood in the eyes of others. I argue that the brain may present itself as an Other, not only through its appearance but through its opposition to selfhood and constant posing threat of robbing one of selfhood.

Returning to the malfunctioning brain as being an Other, we see how the role of the brain is inherently tied to it becoming separate from the self, as the unification of the brain with the self threatens to collapse the boundaries between self and Other – the brain, though it is a part of me, is also not me. In the same way as conjoined twins are forced to construct their personhood individually, the appearing brain is that, which has to be separated from the equation in order for there to be order to the notion of selfhood.

As well as the empirical analyses gain from the psychoanalytical concept of the Other, they also add to this notion by showing the integrative potentials of the Other as in the case of Mr. and Mrs. Jensen, and the use of the Other to obtain a certain goal as in the case of Mrs. Henriksen. With Mrs. Henriksen the Other is a figure that confirms her experience of illness, essentially making it a disease, and with Mr. and Mrs. Jensen the Other is a figure constructed to manage the “true” Other i.e. the Real. The Other always exists, it all depends on where you find it.

This chapter has explored the way in which the brain is located as an Other. The figure of the Other is a central figure, as it helps to illustrate how my informants are struggling with the appearance of their brain, and how this brain, being such a central part of their self, is managed. The dis-location of the experience of fatigue adds to the experience of the brain

as an Other. Through the experience of fatigue the brain becomes located as the place that causes the fatigue, but at the same time we could turn it around and argue that when fatigue presents itself as what I formerly referred to as a *stimmung*, then the brain is located as an Other in fatigue. In essence, we might turn the initial question around about where in the brain fatigue is located, and instead look at how the brain is located in fatigue.

A Question of Location

(Mr. Jensen) Apparently nobody can answer why you are fatigued, and your relatives can't explain it either. I just know that I am fatigued.

In a short story by Jorge Louis Borges (Borges 1999 [1941]), Borges tells of an Empire with some very talented cartographers. To perfect their work of cartography they constructed a map that coincided point for point with what it was to represent. This meant that the map increasingly came to coincide with the mapped territory, eventually covering its representation. Since philosopher Jean Baudrillard took up the story as explanatory of his concept of simulacra (Baudrillard 1994 [1981], 1) the story has become synonymous with postmodernist social science questioning the ideal of representation. Sociologist Zygmunt Bauman (Bauman 2013 [2002]), takes the simulacrum to denote a kind of hyperrealism, which is more real than reality due to the fact that it no longer allows an outside position, from which hyperreality may be viewed:

In a room carpeted wall to wall you never see the floor beneath: when asked, you would be hard put to it to say what the floor beneath was made of – but unless asked, you would hardly ever give the floor another thought.”(Bauman 2013 [2002], 159)

Although Borges' story ends with the refutation of cartography by the following generations living in the Empire – leaving the remains of the map in tatters – Baudrillard takes the story to ultimately convey the erosion between signifier and signified causing the sign to hide reality (Chandler 2007, 81). The story may thus be said to suggest that the ideal of representation does not reproduce reality as much as it constructs a medium, through which a certain reality is configured. Ultimately, the story points to the fact that reality is always mediated and can never present a one to one relationship to an “objective” reality. Thus, the medium through which reality is represented is constitutive of reality.

If we apply the allegory of the map to the overall argument of location in the thesis, what becomes evident is that we all have our own maps where things are located in specific places. We know these maps by heart and often we don't even think about their existence. We embody the routes that we travel, and we share large bits and pieces of the map with others. Sometimes it even seems that we share the entire map, but we quickly find – when we each locate something different places – that maybe our maps are different. We travel this landscape of the map and this landscape constitutes our everyday life and our reality.

It is the filter through which experiences in life are perceived, and we may think we have most things mapped and that we may be able to locate everything. When a stroke happens, it enters life as a sudden tear in the map. The informants in this study can no longer rely on their previous locations or previous maps. Many elements of everyday life have been dislocated and the experiences of fatigue, which this thesis approaches, are not possible to locate on the former and now tattered map. The locations of fatigue no longer provide any meaning to their experiences, and the informants struggle to find their way in this new and alien landscape.

Nonetheless, as the quote by Mr. Jensen illustrates, his fatigue is an experience, which he, although he can't provide it with a meaningful location (although his wife can), is experiencing. In that sense, we could turn the relationship between fatigue and everyday life around. Rather than fatigue being an element in the everyday lives of the informants, their *everyday lives are in fatigue*.

Locating Place and Practice

In the following, I will briefly summarize the chapters of this thesis. Overall, I have explored how experiences of fatigue after stroke can be approached by looking to location. I have emphasized how experiences of fatigue may be located in objects, acts or events, and that this location, as well as practice of location, constitutes an important part of the experience in itself. Thus, I have highlighted how the experience of fatigue is closely associated with where it may be located.

All the chapters are illustrative of the fact that location is both place and practice. Location exists to provide meaning, which it to a certain extent manages through it being so adaptable. Nonetheless, as I show, because location depends on context, it is structured according to a range of different factors in everyday life. By not limiting the concept of location to the location of fatigue, I attempt to portray how the concept may be of further use in future studies, and how its broad application may allow for the opening of a field of study without necessarily having to create generative idealtypes or having to define what an otherwise subjective experience actually is. In essence, the concept of location allows for an analysis of the multitudinous character of fatigue, which can account for the ways in

which the experience and the meaning of the experience may be created. Furthermore, it allows for studying the management of life after stroke by looking at the different practices surrounding the locations.

In the cultural historical chapter “Introducing Fatigue through Acedia and Neurasthenia”, I analyze the position of fatigue within the conditions of acedia and neurasthenia. I discuss how a condition could shape and define the experience of fatigue by locating it within the conditions. Acedia and neurasthenia were conditions at a certain point in time; placed in a certain context that would define the conditions as well as the fatigue within them. I argue that fatigue, through its incorporation in the conditions of acedia and neurasthenia, became tied to class, occupation, morals and pathology. The historical chapter also highlights how the location of fatigue within conditions that initially could only be applied to a limited part of society, represented a way of maintaining social order in society - affirming the social roles as well as hegemonies in society. At the same time, the chapter also illustrates how the location of fatigue within the conditions, and as a sign of the conditions, would make the particular universal. In essence, one's experience of fatigue would become someone else's as well, who would be suffering from the same condition of either acedia or neurasthenia and who had the same position in society. In essence, I argue that neurasthenia and acedia represented conditions that not only accounted for fatigue, but by being specific locations of fatigue, also constructed the experience of fatigue as something specific.

The chapter “An Ethnological Fieldwork” deals with the empirical fieldwork conducted for the thesis. In the chapter, I argue that my initial theoretical approach made me focus on defining fatigue, which I eventually understood stood in the way for what was presented to me in the fieldwork; namely the numerous meaningful locations of fatigue by the informants. Thus, the cultural analytical part of the thesis, which is based on the fieldwork described in the chapter “An Ethnological Fieldwork”, deals with the informants' locations of experiences of fatigue in their everyday life after stroke.

The chapter “A Disrupted Return to Everyday Life” approaches the informants' difficulties in returning to an everyday life after stroke and how fatigue is a reminder of this

inability to return. Through the use of a Heideggerian existentialist and cultural analytical approach to everyday life, I attempt to show how the informants deal with a dislocated fatigue as well as the event of the stroke. I argue that the stroke presents a disruption that makes things that were formerly *zuhandensein* *vorhandensein*. Whereas the *zuhandensein* represents a relation to the world in which things do not appear, *vorhandensein* is the sudden appearance of things in the world that were previously unnoticed but still present. It is my argument that for many of my informants, the task is to reverse this relationship as it makes for a return to everyday life. I argue, that the way this is attempted is by locating the dislocated experience of fatigue, thus facilitating a return to a former everyday life where fatigue is located in the same places; where it is manageable and where it eventually becomes *zuhandensein*. Further, I show how the fatigue may become a *stimmung*. The *stimmung* is what encapsulates one's being and thus the way in which the world is met. This means that there is no distance between one's being and the fatigue, wherefore the provision of a meaningful location is less necessary. Here fatigue manifests itself as a continuous state of being, through which everyday life is configured. In this case, the fatigue becomes an issue for the spouse of the person who has had a stroke; they attempt to locate the fatigue for their partner in order to be able to manage it in their communal everyday life.

In the chapter "The Narratives of Everyday Life" I look at the stroke and how it figures within the narratives of the informants. By approaching the narratives through the hermeneutics of Paul Ricoeur, I show how it is used to account for changes in everyday life, and how the structure of the narrative has an impact on the location of the fatigue. The narrative approach in this chapter allows for an analysis of the temporal character of the informants' narratives as well as it contributes to the argument that several narratives may co-exist.

Expanding on the narrative in the chapter "The Narrative as Communal", I emphasize how the narrative may be communal, and how such a communal narrative can be structured around a certain concept of a symbolic mandate; i.e. how a person with stroke is thought to be like, and how this is a central part of the narrative and the possible locations of fatigue within the narrative.

The chapter “The Regimes of Hope” is based on how the imperative to stay positive and hopeful when confronted with adversity, may in fact have a negative impact on those informants who have given up any hope of progress. The analysis thus portrays how the people (and couples) who feel that their life is deteriorating after stroke, may feel a further moral obligation to stay positive, even though this does not correspond to their situation. For them, the lack of progress may be assumed by others to be caused by them not being adamantly positive.

“Locating Pain” explores how the location of pain may be significant in structuring the informants' everyday lives after stroke. By locating their pain, different acts, objects and events are avoided, and this makes it possible for them to communicate as well as manage their pain.

“Being Normal” represents an analysis of the informants' individual notions of normality. I look at how and where my informants locate what they perceive as non-normal and the way in which this location becomes central in their efforts to achieve an experience of progress after stroke.

The final chapter “This Other Brain of Mine” explores the location of the self in the management of a brain that may be experienced as an “Other” when stroke occurs. Being psychoanalytically inspired, the chapter explores how the notion of self – and in particular locating this self – plays an important part in managing life after stroke. This self is contrasted with the brain and makes the management of the brain easier. The self may be located in different parts of everyday life, in acts that point towards a retrospective self or a spouse that supports the construction of a self. Thus, the notion of a self ensures the informants that they are still the same and in control of their brain. This chapter adds to the overall point that location is not confined to areas of the body and points to the possibility of the conscious constitution of a self outside the materiality of the body.

To a certain extent, one might argue that I have attempted to show that fatigue *is* located in the locations. This seemingly tautological sentence points to the argument that I have

made fatigue equal to where it is experienced – or rather what explains it. Again, I do not claim to provide an answer of what fatigue as a phenomenon actually is but try – through the cultural historical study and the cultural analytical approach to my fieldwork – to analyze how fatigue becomes a meaningful, communicable and thus essentially social experience.

Viewing location as explanation means that an experience like fatigue can be located in all those things that are thought to cause it, be they material, corporeal or immaterial. I argue that location facilitates communication, but does not ensure it. Communication presupposes a recognizable location. Again, this might leave the impression that fatigue is a rigid ontological experience that is communicated through location without affecting the experience itself. This is not the case – rather, the experience of fatigue is tied to its manifestations in locations. In accordance with Heideggerian phenomenology, I argue that fatigue is always before the experience; one does not experience a sensation only to reduce it to fatigue; one experiences fatigue. In effect, locations figure within the experience, and in most cases there is no discrepancy between the experience and the location. Sometimes, however, one may experience fatigue but, in the process of communicating it, find that its location is incommunicable. This is due to the way in which location is negotiated. Locating, as much as it means finding, also means delimiting. Not everything may cause fatigue and not everything can be located as fatigue. To that extent, defining location and thus explanation is a process of negotiation, and sometimes certain locations are placed outside what at the time presents the prevailing locations. The concept of location, in that sense, has an inherently social character.

It is my argument that the definition of location is negotiated within society and in interpersonal relationships, and that different institutions and beliefs have varying impact on this negotiation. In a contemporary Western framework, I argue that a medical conception and definition of location as primarily related to the body has a huge impact on the possibilities of communication. In that sense, I support the tendency in research on doctor-patient discourse that claims that doctors and patients use different modes of language (Charon 1992), while I also argue that there is an interchange between the two. What I stress as being most important is that the cause of fatigue is communicable. As I

show through my empirical findings, there are ranges of different locations of fatigue that are not only explained by the body but by acts, events or objects. To sum up, fatigue is always situated, but in order to communicate it, it needs a location to explain it. In essence, location has to provide a rationale, and it has to provide this rationale within a social framework. This is what makes a cultural/social/ethnological analysis the obvious approach to the study of the locations of fatigue.

The Stroke Revisited

In the introduction to the thesis, I provided a short outline of qualitative studies on stroke and emphasized how the present study would add to literature on *life after the acute event* by proposing to look at the location of an experience such as fatigue. Apart from the emphasis on location, the present thesis has made other contributions to the literature. Amongst these contributions I would emphasize the specific existential approach to life after the acute event. Previous studies have been engaged in the exploration of existential aspects of life after stroke – some of which have utilized the existential theory of Rosemarie Rizzo Parse (Pilkington 1999); a nursing theorist developing her theory from the likes of Heidegger, Dilthey, Sartre and Merleau-Ponty (Parse 1981) – but in most cases these studies have aimed at assessing quality of life after stroke. In that sense they have presented a qualitative response to more quantitative studies of quality of life, and in doing so emphasis has been on *what* is meaningful in peoples lives following stroke, and not on *how* meaning is created (Secrest and Thomas 1999). By approaching life after stroke with an emphasis on experiences of everyday life rather than quality of life, I have examined how a stroke may question one's existence and how it may pull one out of a relationship to everyday life; a relationship of *zuhandensein* to everyday life. Rather than focusing on the exact experiences of loss after stroke, the *zuhandensein* and *vorhandensein* analysis of everyday life emphasizes how elements formerly *zuhandensein* become *vorhandensein* and how this impacts one's being-in-the-world.

I would also point to the exploration of the brain as an Other, and the importance of the self in the management of life after stroke. Instead of assuming the existence of an ontological self, I analyze how the self is a significant construction in contemporary society that, in the case of my informants, becomes of even greater importance after stroke. To

that extent, I highlight the clash between the management of the self and the management of the brain as an Other. As so much of a person's personality is commonly presented as being located in the brain (Andersen et al. 2012), I approach how my informants deal with the brain through putting an emphasis on their self while othering the brain. A number of articles do treat a self-body split among people who have had a stroke (Ellis-Hill, Payne, and Ward 2000; Doolittle 1992; Cant 1997), but they do so stressing the entire body and not the brain, while simultaneously not examining the role of the self in relation to the body. Rather these articles treat the self as an ontological entity that is confronted with a body acting out.

Finally, I would single out the chapter "The Regimes of Hope" in particular because of the way in which it points to a central issue for some post-stroke patients, who feel that they have to stay positive and to hope almost as a moral imperative. In that respect the chapter pokes at a very stabilized notion within much self-help literature on stroke recovery that emphasizes the need to stay positive and to hope. Thus, it challenges the presumably well-intentioned emphasis on positive thinking when encountering adversity, and points to the way in which, when it is experienced as a moral dictum, it has a negative impact on the couples who have not experienced much progress and who have given up hope that things will get better.

Perspectives

As mentioned in the introduction, the thesis represents one route out of many. This implies that some areas have not been under as close scrutiny as others. The question of the relation between discourses of fatigue in everyday life in connection to medical discourse is one of the areas less explored. To explore this question further, I would suggest taking a semiological approach.

Although a semiological³⁷ approach has been referred to a couple of times during the thesis, I have not been consistent in my use of semiology. This is partly due to the often well-founded notion of a discrepancy between specific phenomenological approaches and

³⁷ Semiology and semiotics are most often used interchangeably, although there are some that differ between semiology as representing the tradition of Ferdinand Saussure and semiotics as representing the tradition of Charles Sanders Pierce

a semiology, which has intrinsic links to structuralist thought. From a radical phenomenological position that privileges subjective experience over intersubjective – arguing that reality is prior to any sign-system – to a radically social constructionist that argues that sign-systems are not reflections of reality but constructions of reality, the line of unbridgeable separation has been drawn. However, as I have attempted to show throughout the thesis, a phenomenological and existentialist approach as that outlined by Heidegger always highlights how human existence takes place in context, and that language and experience are thus inseparable. No experience is “presuppositionless”, and this insight is indeed important to keep in mind. To that effect it has come to my awareness that there is no significant reason – in terms of the status of reality – as to why one could not operate with a phenomenological theory along with a semiotic, as has been approached by a phenomenologist such as Alfred Schutz in *The Phenomenology of the Social World* (Schutz 1967). Thus my proposal for a further semiotic study would be not to “bracket the referent” – something which Saussure attempted to achieve, which essentially meant that he would focus solely on structure as an entity in and of itself – but to focus instead on a more social semiotic approach such as that of a critical discourse analysis. This would be of great significance to the study of experiences, and in particular a study of fatigue as a social experience. By focusing on a critical discourse analysis, such a study could contribute with a semiotic denaturalization of what is presented as the reality of fatigue, and by doing so point to the structures of power that have been established and that are continuously confirmed, within the sign-systems themselves. This would essentially entail an approach that would investigate the sign-systems of fatigue as something more than a neutral mediator of experience, and more similar to an arena for the construction of fatigue and the possible experiences of fatigue. As semiotician Daniel Chandler puts it by reference to cultural theorist Stuart Hall:

...our ‘systems of signs...*speak to us* as much as we speak in and through them’ (Hall 1977, 328) *see* (Curran, Woollacott, and Gurevitch 1979, 328). We are thus the subjects of our sign-systems rather than being simply instrumental ‘users’ who are fully in control of them. While we are not determined by semiotic processes we are shaped by them far more than we realize (Chandler 2007, 216)

Such a semiological analysis would focus on both *parole* and *langue*, thus highlighting the relation between medical discourses on fatigue and the everyday usage of these discourses

within sign-systems. This could admittedly seem to provide for a more structuralist study emphasizing the importance of medical discourse in the construction of everyday discourses. However, it could be turned around so as not to provide any sort of primacy to medical discourse and in the process of doing so show how medical discourse is situated within a sign-system defining what can be articulated – and more importantly what can be constructed as medical facts. This would also help in providing a more thorough answer to one of the questions posed in the PhD advertisement, namely the relationship between fatigue in science and everyday life. The present thesis has allowed for a focus on everyday life due to the nature of the empirical material. Thus the power structures inherent in the definitions of fatigue have not been directly addressed – although they are constantly present in the historical analysis as well as in the chapter “The Regimes of Hope” – but could potentially have been further developed. However, I have not seen it within the scope of the present thesis to do so – rather I have addressed it implicitly through the analyses of locations. In direct extension of my approach to fatigue as related to location, it could thus be relevant to look more thoroughly at the power structures built into the definitions of locations. As semiotics makes us aware, the structure of sign-systems and their possibilities of providing meaning is not limitless, resting on individual perception – rather sign-systems at all times have certain sets of possible meanings that are, however, all apt for change. Whereas I have approached these locations as being structured through class and position in society, everyday life, narratives, notions of normality, symbolic mandates etc., I have not gone in depth with an analysis of how the location of fatigue may also reflect a political struggle, as well as how the sciences influence what can be utilized as meaningful locations – something which could become more obvious through a semiological study.

A Final Location

In the month of November 2012 a number of international newspapers featured an article about Sandy Island near New Caledonia. The Island was, according to the National Public Radio (NPR) in the US³⁸, first mentioned by James Cook in 1774. Since then Sandy Island featured on a range of maps and was as of November 2012 possible to find

³⁸ <http://www.npr.org/blogs/krulwich/2013/03/13/174203234/pacific-island-bigger-than-manhattan-vanishes>

on Google maps, shown as an Island approximately the size of Manhattan. However, on the 21st of November that year, a group of geologists sailed to where the Island should have been but saw only open sea. Rather than having been one of many unfortunate islands victim for flooding due to climate change, it turned out that the island had in fact never had a material existence. Of course this surprised scientists and accordingly newspapers around the world. I myself was baffled by the news, naively believing that all contemporary maps, in particular Google maps, relied on satellite photos that rendered pictures of reality as it was at a particular moment in time. To me it was a crack that made me aware of the holes in the map – and a crack that emphasized the fact that we may think we have everything mapped and that we can locate every island in the world, but that this mapping and locating is in truth a medium through which we perceive reality. Thus, Sandy Island, is a place from where we can see reality as mediated. It reminds us that all our locations are apt for change; that to locate fatigue is a social as well as embodied experience that may be radically altered if stroke happens.

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Fieldwork Index

Main Informants

Mrs. Henriksen

Mrs. Henriksen is in her mid-forties: She lives in a suburb in Copenhagen with her husband and three of her kids in an apartment. She has five kids in total between the ages of 19-27. She is receiving an early retirement pension and her husband lost his job a couple of years ago.

Interview length: 3 hours

Date: 11/05/2011

Mr. and Mrs. Olson

Mr. and Mrs. Olson is a retired couple in their early 80'ies who live in an apartment on Amager, Copenhagen. Mr. Olson had a stroke in the autumn of 2010. He has not sustained any kinds of disability after the stroke, but his wife feels that something has changed and he tends to agree. They used to own a dry-cleaner's before they retired.

Interview length: 45 min.

Date: 12/05/2011

Mr. and Mrs. Nielsen

Mr. Nielsen is in his late 70ies and Mrs. Nielsen is in her mid 70ies. They live in a house on Amager, Copenhagen and are both retired. Mr. Nielsen had a stroke shortly after he retired as a mason in the late 90ies, and was partly paralyzed after his stroke. Through intensive training just after his stroke he regained some of his physical capabilities, which allowed him to be able to walk short distances with a cane. His wife has taken care of him ever since his stroke.

Interview length: 1 hour 20 min.

Date: 24/05/2011

Ms. Petersen

Ms. Petersen is in her mid 50ies. She lives alone in an apartment in a suburb in Copenhagen and receives a disability retirement. She has never been married and has a daughter in her mid 20ies. Mrs. Petersen had a stroke in 2011. When I interview her, it's

been half a year since she had her stroke. The stroke has left her mildly impaired on her left side.

Interview length: 1 hour 25 min.

Date: 22/06/2011

Mr. and Mrs. Jensen

Mr. and Mrs. Jensen is a retired couple both in their early 70ies. They live in a house north of Copenhagen. Mr. Jensen had a series of strokes in the late nineties, but was able to return to his work as a smith after the first couple of strokes. The last stroke paralyzed the left side of his body making it impossible for him to get back to work. His wife has taken care of him ever since.

Interview length: 1 hour 15 min.

Date: 29/06/2011

Mrs. Eriksen

Mrs. Eriksen is in her early 80ies and retired. She lives alone in an apartment in the outskirts of Copenhagen. She moved to this apartment some years ago because of the vicinity to her daughter's house. She had a stroke in the month of July 2012, which didn't cause her any paralysis besides a slight hearing loss.

Interview length: 45 min

Date: 20/11/2012

Mrs. Herschel

Mrs. Herschel is in her late 40ies and works for a big national company. She lives in a house in a suburb in Copenhagen with her husband and has no children. Three months prior to her stroke, she had gone on sick leave due to stress. When I interview her, I meet her at her work, which she has returned to for a couple of hours every week until she at some point is ready to work full time.

Interview length: 45 min.

Date: 28/11/2012

Mrs. Albrechtsen

Mrs. Albrechtsen is in her late 40ies and lives with her husband in a non-detached townhouse in Copenhagen. She has four kids between the ages of 20-30 and four younger grandchildren. She had a stroke in the summer of 2012. Since then she has been very

fatigued and has a hard time remembering different tasks, which is a challenge whenever she goes to work as a nursery teacher.

Interview length: 1 hour

Date: 04/12/2012

Mrs. Johnsen

Mrs. Johnsen is in her mid 80ies. She lives alone in a suburb in Copenhagen. She has two daughters both in their 50ies and a couple of grandchildren. One of her daughters lives close by. She had a stroke in the summer of 2013 and is currently in a wheelchair although the stroke is not the cause of this.

Interview length: 50 min

Date: 30/12/2012

Ms. Krogh

Ms. Krogh is a retired woman in her mid 70ies who lives by herself in a suburb in Copenhagen. She had two daughters but lost one of her daughters tragically a couple of years ago. She had a stroke in the early months of 2013. She experienced an impairment of her left arm following the stroke.

Interview length: 40 min

Date: 11/12/2012

Mrs. Poulsen

Mrs. Poulsen is in her mid 60ies and lives in a non-detached townhouse in Copenhagen with her husband. They are both retired. She has a daughter, four grandchildren and seven great-grandchildren. She had a transient ischemic attack in the summer of 2012 and then one more ten days later.

Interview length: 50 min

Date: 06/02/2013

Observations

Observations at Glostrup Hospital

Dates: 03/03/2011, 10/03/2011, 17/03/2011, 05/05/2011, 11/10/2011

Resumé

”Et spørgsmål om lokalisering – Et liv med træthed efter en blodprop i hjernen.”

Nærværende ph.d. afhandling tager udgangspunkt i oplevelsen af træthed efter apopleksi. På baggrund af et kvalitativt feltarbejde blandt personer, der har haft en blodprop i hjernen, undersøger jeg, hvordan de oplever træthed. Dette gør jeg via en etnologisk undersøgelse af, hvordan informanterne lokaliserer trætheden i deres hverdagsliv. Med udgangspunkt i deres lokalisering som både sted og praksis viser jeg, hvordan blodproppen dis-lokaliserer og re-lokaliserer oplevelsen af træthed, og hvorledes en ny lokalisering af træthed fordrer nye meningssammenhænge.

Som baggrund for den empiriske analyse foretager jeg, i den første del af afhandlingen, et kulturhistorisk studie af de to tilstande *acedia* og *neurasteni*. Jeg viser, hvorledes træthed, i begge tilfælde, er blevet behandlet som et lokaliserbart element i en specifik kontekst og derved defineret af de to tilstande.

I anden del af ph.d. afhandlingen går jeg kulturanalytisk til værks og behandler informanternes oplevelser af træthed i hverdagslivet. Her betoner jeg informanternes forsøg på at give oplevelsen af træthed mening, såvel som at gøre trætheden kommunikerbar, ved at lokalisere trætheden i forskellige områder af hverdagslivet. Via analyser af informanternes narrativer, deres oplevelser: af ”håbsregimer”; af smerte; af normalitet og stigmatisering; af deres selv i forhold til deres hjerne, undersøger jeg, hvorledes informanterne forsøger at vende tilbage til et hverdagsliv via genkendelige, meningsgivende og kommunikerbare lokaliseringer.

Ved hjælp af en eksistentielistisk orienteret tilgang undersøger jeg, hvorledes træthed både kan være en afgrænset oplevelse med en specifik lokalisering, lige så vel som det kan være konstituerende for en måde at se verden på. I den sammenhæng illustrerer jeg, hvorledes lokalisering er såvel praksis som sted. Således er lokalisering et muligt greb for fremtidige etnologiske studier af oplevelser.

Summary

“A Question of Location – Life with Fatigue after Stroke”

This thesis treats the experience of fatigue after stroke. Based on a qualitative fieldwork conducted among people who have had a stroke, I explore how they experience fatigue. I do this by way of an ethnological examination of how the informants locate fatigue in their everyday lives. By approaching their location as both place and practice, I illustrate how the stroke dislocates and relocates the experience of fatigue and how a new location of fatigue calls for new meaningful contexts.

In the first part of the thesis - as a background for the empirical analysis – I carry out a cultural historical study of the two conditions of *acedia* and *neurasthenia*. I illustrate how fatigue in both cases has been treated as a locatable element in a specific context and thus defined by the two conditions.

In the second part of the thesis I do a cultural analytical study of the informants' experiences of fatigue in everyday life. I accentuate the informants' attempts at providing their experiences of fatigue with meaning, as well as making their fatigue communicable by locating fatigue in different places of everyday life. Through analyses of the informants' narratives and their experiences of: “regimes of hope”; pain; normality and stigma; their self in relation to their brain, I examine how the informants attempt to return to everyday life through recognizable, meaningful and communicable locations.

Informed by an existentialist approach I examine how fatigue may both be a delimited experience with a specific location as well as it may be constitutive of a way of perceiving the world. In this context, I portray how location is both practice and place. Consequently, the concept of location is a possible approach for future ethnological studies of experiences.